



# Infected Blood Inquiry

# The Report

## Response of Government and Public Bodies

- The Initial Government Response 1985-1988
- HIV Haemophilia Litigation
- Macfarlane Trust
- Government Response to HIV Infections through Blood Transfusion or Tissue Transfer
- Eileen Trust
- Government Response to Hepatitis C Infections
- Skipton Fund
- Government Response to the Archer Inquiry
- Caxton Foundation
- Medical Records
- National Support Schemes
- Access to Treatment
- Inquests, Fatal Accident Inquiries and Death Certificates

6 of 7

20 May 2024  
HC 569-VI

Infected Blood Inquiry

# **The Report**

Presented to Parliament pursuant to section 26 of the  
Inquiries Act 2005.

20 May 2024  
HC 569-VI



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# Contents

<b>6.1 The Initial Government Response 1985-1988</b>	<b>2</b>
<b>6.2 HIV Haemophilia Litigation</b>	<b>19</b>
<b>6.3 Macfarlane Trust</b>	<b>59</b>
<b>6.4 Government Response to HIV Infections through Blood or Tissue Transfer</b>	<b>130</b>
<b>6.5 Eileen Trust</b>	<b>148</b>
<b>6.6 Government Response to Hepatitis C Infections</b>	<b>156</b>
<b>6.7 Skipton Fund</b>	<b>194</b>
<b>6.8 Government Response to the Archer Inquiry</b>	<b>231</b>
<b>6.9 Caxton Foundation</b>	<b>265</b>
<b>6.10 Medical Records</b>	<b>282</b>
<b>6.11 National Support Schemes</b>	<b>312</b>
<b>6.12 Access to Treatment</b>	<b>345</b>
<b>6.13 Inquests, Fatal Accident Inquiries and Death Certificates</b>	<b>399</b>

## 6.1 The Initial Government Response 1985-1988

This chapter charts the Government's resistance to compensation in the period from 1985 to 1988, referencing political and financial considerations. It discusses how the Government formed and maintained its view that nothing warranting compensation had occurred, and examines the decision of the Government to make a one-off ex gratia payment in November 1987.

### Key Dates

**February 1985** first public statement from the Government rejecting calls for compensation.

**January 1987** *The Northern Echo* begins a campaign for compensation and the Government maintains that there will be no state compensation.

**February 1987** Secretary of State seeks legal advice as to the possible liability of the NHS.

**May 1987** Tony Newton gives evidence to the House of Commons Social Services Committee maintaining the position of no scheme to compensate for “*unavoidable adverse effects*” of medical treatment.

**July 1987** Tony Newton considers the option of providing a sum to the Haemophilia Society.

**August 1987** Tony Newton writes to John Moore about the “*considerable parliamentary and public pressure ... to do something*”.

**3 November 1987** John Moore and Tony Newton meet the Haemophilia Society.

**4 November 1987** John Moore writes memorandum proposing a once and for all payment to the Haemophilia Society to distribute to people infected.

**10 November 1987** Cabinet Sub-Committee on AIDS considers the memorandum.

**16 November 1987** Government announces a grant of £10 million to the Haemophilia Society to enable it to establish a special fund.

### People

**Kenneth Clarke** Minister of State for Health (1982 - 1985)

**John Moore** Secretary of State for Health and Social Services (1987 - 1988)

**Dr Roger Moore** civil servant in a policy division within the DHSS (1985 - 1988)

**Tony Newton** Minister of State for Health (1986 - 1988)

**Baroness Trumpington** Parliamentary Under-Secretary of State for Health (Lords) (1985 - 1987)

### Abbreviations

**DHSS** Department of Health and Social Security

**UKHCDO** United Kingdom Haemophilia Centre Directors' Organisation

The Government decided against the provision of any form of “compensation” to people infected with HIV at an early stage. On 25 February 1985, Kenneth Clarke, the then Minister of State for Health, stated, in response to a question as to whether he had any plans to offer compensation to people contracting AIDS as a result of contaminated blood supplied by the NHS, “*There has never been a general State scheme to compensate those who suffer the unavoidable adverse effects which can unhappily arise from many medical procedures.*”<sup>1</sup>

In other words, the Government had no plans to offer compensation. And it had already decided, at the outset, that no one could or should be held responsible – no one was at fault, this was just one of those things, an unhappy but inevitable consequence of treatment.

The Government’s characterisation of the transmission of AIDS, with its high mortality rate and lack of treatment, as one of the “*unavoidable adverse effects which can unhappily arise from many medical procedures*” was inappropriate, ill-considered and demonstrated a lack of curiosity about what had actually happened. It set the tone, however, for the Government’s response for many years.

By 1986 the suffering of people who had been infected with HIV through blood products was plain to see. Some had already developed AIDS, for which there was no effective treatment. Some had already died. Others were being subjected to isolation and social stigma. This stigmatisation manifested itself not only within communities and even families, but also within the medical and allied professions: “*doctors who do not understand the meaning of the test; dentists who will not now treat people with haemophilia*”.<sup>2</sup> Some had to face up to the prospect of never having children. Insurance and mortgages were becoming difficult or impossible to obtain. Employers were terminating employment or refusing to engage people. Children were facing hostility and difficulties at school. Some found themselves living a double life, concealing the truth of their condition from work colleagues, friends and family.

Others were witnessing their children, parents, partners, siblings undergo horrific physical and mental suffering, and dying, while they desperately tried their best to care for them.

It would be inconceivable that the Government did not become aware of some of the first deaths from AIDS transmitted by blood products. Particular prominence in the media was given to the early victims of infected blood. The Cardiff patient, Kevin Slater, had been thought to be suffering from AIDS in spring 1983. Over the following two years his health

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1 Hansard written answer on AIDS 23 February 1985 PRSE0003350. A press report in the British Medical Association’s magazine referred to backbench MP Christopher Chope wanting the Government to sue the US exporters of the infected supplies. Kenneth Clarke was described as fiercely resisting the suggestion of compensation and flatly rejecting legal action. *The Doctor Clarke resists call for AIDS compensation* 7 March 1985 p1 WITN0771193

2 The Effect of HTLV-III Antibodies on the overall lifestyle of people with haemophilia 17 February 1986 HSOC0023228\_001. This was, after all, the year in which the chief constable of Greater Manchester called AIDS a self-inflicted wound and suggested that people at risk were “*swirling around in a human cesspit of their own making*”. The Times *Ministers dismiss Anderton’s tirade* 13 December 1986 HSOC0015800, and Edwina Currie said something along the lines “*Good Christian people who wouldn’t dream of misbehaving will not catch AIDS*” (although see her statement for the explanation as to the context in which that remark was made: Written Statement of Edwina Currie Jones paras 3.11-3.19 WITN5287001).

deteriorated and he was repeatedly admitted to hospital. He died on 23 June 1985, aged 22. By the time of his death he was “*grossly emaciated*” and “*generally weak and had become unable to hold even a glass of milk for himself and his parents had to feed him.*”<sup>3</sup>

The first death from AIDS of a person with haemophilia in the UK was in August 1983: Peter Palmer was a 57 year old grandfather, treated with US concentrates, whose death was reported in the Mail on Sunday on 2 October 1983<sup>4</sup> and would in any event have been known to the Department of Health and Social Security (“DHSS”), his death having been discussed at a meeting of the reference centre directors attended by Dr Diana Walford on 19 September 1983.<sup>5</sup>

Media prominence was given in Scotland to Terry McStay, who was the second person with haemophilia whose death was reported. He was 34 when he died of AIDS on 3 November 1984, having first become ill in 1983. His death was, as his brother-in-law explained to the Inquiry, “*front page news. Terry was the first haemophiliac to die of AIDS in Scotland*”.<sup>6</sup> He “*just got weaker and weaker and all we could do was help relieve his pain.*”<sup>7</sup>

David Tomkinson had been diagnosed in 1985 and died on 12 April 1987, aged 28. Jacqueline Tomkinson, his wife, told the Inquiry:

*“He was frightened about infecting our elder daughter Rebecca, our unborn child Helen, and also me. He was a really jolly, outgoing, cheeky guy, but behind closed doors it was hard. David was withdrawn and down. Some days he would cry and I would have to get his Mum and Dad to come over to try and talk to him. He was so frightened of dying ... his health deteriorated rapidly and within a year and half he was dead ...*

*We almost lost our family home. I had to rely on family members to help us pay our mortgage and look after my children whilst I worked and nursed my dying husband. We applied for income support, but it did not come through until after David died.”*<sup>8</sup>

One woman described how her father became progressively more ill in 1985 and eventually had to retire on medical grounds at the end of the year. “*Daddy was very strong and carried on, but physically became very frail ... I never gave my mother credit for how strong she*

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3 Counsel Presentation on the first Cardiff AIDS patient: Kevin Slater January 2021 p15 INQY0000321. His sister-in-law’s understanding was “*the hospital staff would not bring food into Kevin’s room near the end of his life, no one wanted to enter his room. It was really sad; he was not treated like a human being. When he passed away no one wanted to go into his room. The funeral director did not want to enter his room to collect his body. Trying to arrange a funeral was difficult, no one wanted to know. It was a difficult and horrible time.*” Written Statement of Lynda Maule para 33 WITN3517001

4 Mail on Sunday *The scandal of Peter Palmer’s death* 2 October 1983 HSOC0016112

5 Minutes of Haemophilia Reference Centre Directors meeting 19 September 1982 p4 PRSE0003196

6 “*the body was in the house but the curtains were certainly drawn, and if you opened the curtains then the press were outside on the pavement and the photographers, the cameras would start flashing and you’d close the curtains quickly.*” John McDougall Transcript 3 July 2019 pp62-64 INQY1000026

7 Terry McStay’s GP quoted in: Daily Mail *Seven-month hell of man dying from AIDS* 20 November 1984 p1 WITN2850002

8 Written Statement of Jacqueline Tomkinson paras 14-16, para 25 WITN2807001

*was, because at the time I believed Daddy was the strong one. She carried the family – ran the house, had the children well turned out – even though her heart was breaking because her husband was dying.”<sup>9</sup>*

Graham Polumbo was just 15 years old when he died, from AIDS, in November 1986, having been extensively treated with factor concentrates, including US products. His mother, Janette Johnson, told the Inquiry that he was a “wonderful son” and an “extremely kind hearted boy.” Although extremely poorly as a result of HIV, he managed to attend school but it was “heart breaking to see him come home upset after school, and in tears, every day because the other children had been so cruel to him.” She did not know how she “managed to cope in the days and months after Graham’s passing. I just existed.”<sup>10</sup>

Infected individuals, clinicians, and MPs began to raise the question of compensation with increasing urgency.

One such individual was Nicholas Medley. He had haemophilia and was infected with HIV following treatment with commercial factor concentrates. In April 1986 he wrote to his MP – John Patten – raising the question of compensation. He talked about the lasting anxiety for those infected and their families of waiting to see if the symptoms of AIDS presented themselves; the enormous difficulties in establishing relationships; the absence of any effective treatment, let alone a cure. He hoped that this did not seem “an unreasonable point of view”.<sup>11</sup> The response from Baroness Trumpington, the Parliamentary Under-Secretary of State for Health in the House of Lords, epitomised the Government’s position. After the expression of deepest sympathy, she stated:

*“there has never been a general State scheme to compensate those who suffer the unavoidable adverse effects which can in rare cases unhappily arise from some medical procedures. Compensation is awarded by the Courts where negligence has been proved ... Before the availability of heat-treated Factor VIII, the possible risks of unheated Factor VIII had to be weighed against the effects on the lives of haemophiliacs of ceasing to have treatment. Doctors treating haemophiliacs were, we believe, careful in explaining these risks to their patients ... the whole range of health services is available to help HTLV III antibody positive patients.”<sup>12</sup>*

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9 Written Statement of ANON paras 23-24, para 40 WITN3777001

10 Written Statement of Janette Johnson paras 24-33 WITN1755001

11 Letter from Nicholas Medley to John Patten 4 April 1986 HSOC0023114, Letter from Nicholas Medley to John Patten 21 April 1986 DHSC0004528\_061

12 Letter from Baroness Trumpington to John Patten 14 May 1986 HSOC0023119. At the time of writing to his MP in 1986 Nicholas Medley had not developed AIDS. That was not to remain the position. He died, aged 41, from AIDS in 1994 “after years of mental and physical anguish”. His family wrote again to John Patten that year. Referring to the litigation, they explained that he had “very reluctantly accepted what he regarded as the derisory sum of £23,500 for a life of uncertainty and worry.” Letter from Christopher Wallworth to John Patten 16 June 1994 DHSC0006173\_082. The Secretary of State for Health, Virginia Bottomley, wrote in response asserting that the medical treatment given prior to 1985 was “the best available, in the light of medical knowledge at the time. In the Government’s view, those who became infected through blood products did so through no one’s fault.” Letter from Virginia Bottomley to John Patten 5 July 1994 DHSC0006173\_079



Two comments. First, it is difficult to understand how or on what basis the Government apparently formed the belief that doctors had carefully explained the risks of factor concentrates to their patients.<sup>13</sup> There is no evidence whatsoever of any attempt to glean information about this from those patients. If the Government was told this by doctors (as to which there is also no evidence), it was an untruth that was uncritically accepted by the Government. If the Government was not so told by doctors, then there was no basis whatsoever for its belief.<sup>14</sup> Second, the statement that the balance of risks “*had to be weighed*” is cast in a manner which suggests approval for doctors imposing their view as to the appropriate treatment on their patients.

One clinician who raised the compensation question was Dr Charles Forbes, director of the Glasgow Haemophilia Centre and chair of the United Kingdom Haemophilia Centre Directors’ Organisation (“UKHCDO”), who wrote to Margaret Thatcher in December 1986. He expressed his belief that “*this tragedy ... represents one of the greatest medical catastrophes ever ... Their whole lives lie in ruins.*” He invited “*your Government*” to explore the possibility of a compensation scheme “*which would go some way to ameliorate the plight of this most unfortunate group of patients.*”<sup>15</sup> It was Baroness Trumpington, rather than the Prime Minister, who replied, repeating that there was no state scheme to compensate those who “*like haemophiliacs infected with the AIDS virus, unfortunately suffer adverse effects from their medical treatment.*” This letter, instead of referring to the “*whole range of health services*” available, asserted that “*the full range of social security benefits*” was “*of course*” available to those who were infected.<sup>16</sup>

In November 1986 Tony Newton, who had succeeded Kenneth Clarke as Minister of State for Health in September, answered a parliamentary question seeking to know when the DHSS had first become aware of AIDS, when it first became aware that AIDS was sexually transmitted, and when it first became aware that it could be transmitted through blood and blood products.<sup>17</sup> In his reply, he stated:

*“First reports about the disease were received from America in 1981 and the first case of AIDS in the United Kingdom was diagnosed at the end of that year.*

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13 The same assertion was contained in another letter from Baroness Trumpington, to Anthony Nelson MP. Letter from Baroness Trumpington to Anthony Nelson March 1986 DHSC0000194

14 This assertion also appears in an undated briefing pack. Haemophiliacs and AIDS p5 DHSC0002291\_004. Lord Norman Fowler told the Inquiry that Baroness Trumpington was pretty new to the post and that he thought most ministers would have queried that particular sentence. Lord Norman Fowler Transcript 22 September 2021 p114-115 INQY1000145. This is not intended as a criticism of Baroness Trumpington whose words no doubt reflected the briefings or information that she had been given by civil servants.

15 Letter from Dr Forbes to the Prime Minister 16 December 1986 SCGV0000013\_087

16 Letter from Baroness Trumpington to Dr Forbes 19 January 1987 SCGV0000013\_016. Similar letters were sent by Scottish Office ministers in response to letters from Dr Christopher Ludlam. See for example Lord Simon Glenarthur’s letters to John Home Robertson MP and Archy Kirkwood MP: Letter from Lord Glenarthur to John Home Robertson 2 March 1987 SCGV0000014\_038, Letter from Lord Glenarthur to Archy Kirkwood 2 March 1987 PJON0000072\_088

17 On the same date – 20 November 1986 – *The Times* published a letter from Dr Peter Jones, calling on the Government urgently to provide “*constructive and compassionate help*”. Letter from Alex Fletcher to Lord Glenarthur 26 January 1987 p3 SCGV0000014\_044

*The possibility that AIDS could be sexually transmitted was suggested at that time<sup>18</sup> ... [The DHSS] became aware in 1982 of reports from the United States of America that haemophiliacs were contracting AIDS. Although the mechanism of infection was not known it was presumed that it had been transmitted through the use of blood products such as factor VIII.<sup>19</sup> Evidence that the AIDS infection could also be transmitted by blood transfusion emerged from the United States of America in 1983.”<sup>20</sup>*

On 12 January 1987 *The Northern Echo* began a campaign it described as “*the public cry for justice*” seeking compensation for people with haemophilia infected by AIDS as a result of their treatment.<sup>21</sup> The newspaper anticipated that a number of people were preparing to take legal claims to court. The prospect of such claims being made against the Government, a health authority, or a treating doctor was a live topic.

On the same date as *The Northern Echo* began its week-long series of pieces, Tony Newton was asked specifically, in a parliamentary question, if the Secretary of State would take steps to compensate those with haemophilia who had been infected with AIDS by Factor 8 imported from the US. He undertook to give an answer as soon as possible.<sup>22</sup> No willingness or agreement to compensate emerged.

And on that same date, Tony Newton was sent a briefing, in anticipation of an appearance at the Health Committee the following day, in which the suggested answer to a question about compensation was “*We will be considering this question fully since it has far reaching implications. Officials are preparing a full report on all of the problems faced by haemophiliacs.*”<sup>23</sup>

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- 18 Compare with the complaint of the Haemophilia Society in its submissions that it was never told in 1983/84 that AIDS might be transmitted by sex between man and woman, and this was not understood clearly at the time by many of its members. This is in the chapter on the *Haemophilia Society*.
- 19 Compare with the approach of the Government during 1983 that there was no conclusive proof that blood products transmitted or were the cause of AIDS.
- 20 Hansard written answer on AIDS 20 November 1986 pp2-3 CBCA0000027\_008
- 21 *The Northern Echo Campaign wins support and starts debate* HSOC0002971\_003. The campaign, influenced heavily by Dr Peter Jones, who was the haemophilia centre director in Newcastle, by John Prothero, and by the Haemophilia Society, is described in these terms: “*Today we begin a major series on AIDS. Echo writers have been speaking to sufferers and potential victims and assessing the claim for compensation by haemophiliacs who have been infected via blood transfusions.*” *The Northern Echo Infected blood has given AIDS to haemophiliacs* HSOC0002971\_001. There follows a series of pieces about individual experiences and an interview with Dr Jones.
- 22 Hansard written answer on AIDS 12 January 1987 CBCA0000027\_083. The answer that was then given, on 15 January 1987, was that “*There is no state compensation scheme for those who, like haemophiliacs infected with the AIDS virus, unfortunately suffer adverse effects from their medical treatment.*” Hansard written answer on AIDS 15 January 1987 DHSC0014947\_046
- 23 Memo from Bernie Merkel to Joanne Herrick 12 January 1987 WITN0771195 and Briefing material for AIDS questions 12 January 1987 p11 WITN0771196. It is not clear what was meant by a full report. There is no evidence of any evidence gathering exercise, but on 13 January 1987 Malcolm Harris, the assistant secretary in HS1, writing to colleagues, referred to the increasing pressure for compensation and the need to go to ministers in the near future with a “*full submission*” on the subject. His view was that there was little alternative but to adhere to the existing line: “*Apart from the inherent cost of a scheme for haemophiliacs it would be difficult to distinguish their problem from that of others who may have fallen foul of drugs with adverse reactions. It might also open up the whole subject of no-fault compensation for medical accidents.*” Memo from Malcolm Harris to Dr Alison Smithies and others 13 January 1987 p1 WITN0771210. This minute elicited a warning from the Finance Division

It was clear that the Government was continuing to resist compensation.

Reporting in early February 1987 *The Northern Echo* said it had been told by Tony Newton that paying compensation to AIDS victims with haemophilia could lead to “*very great difficulties*”. It would be hard to distinguish their claims from those of other people who had suffered as a result of medical incidents involving no question of negligence.<sup>24</sup> Dr Roger Moore, a civil servant in a policy division within the DHSS,<sup>25</sup> prepared a briefing note for an interview with *The Northern Echo* in late February repeating this line.<sup>26</sup> The DHSS’s view<sup>27</sup> at the time was that the “*adverse effects*” people with haemophilia had suffered were “*unavoidable*”.<sup>28</sup>

Information gathered by Dr Alison Smithies and provided to colleagues in mid February 1987 included the following advice with regard to compensation:

*“Their position is pitiful and has attracted great sympathy in particular because of perceived stigma of the disease which is associated with promiscuous sexual activity. The equally sad fact that a number of haemophiliacs will undoubtedly die of chronic hepatitis as a result of non-A non-B infection has not been recognised publicly ... I find it difficult to advocate that there are any special circumstances surrounding the care of haemophilia which makes their case for compensation greater than that of other patients who take medicines which kill them. That is, of course, provided the doctors caring for the patients have prescribed their treatment in a proper manner.”*<sup>29</sup>

This was a remarkable statement in three respects. The first is the acknowledgement that a number would die from non-A non-B Hepatitis and that this had not been publicly recognised, without any suggestion that steps should be taken to ensure that the public became aware. The second is the casual reference to “*medicines which kill*” and the implicit suggestion that there was nothing exceptional or “*special*” or particularly troubling about that. The third is the proviso at the end – no special circumstance justifying compensation **provided** that doctors had prescribed the treatment in a proper manner. Prescribing treatment in a proper manner in the context of “*medicines which kill*” would have to involve close and careful attention to alternative, less dangerous forms of treatment, and the clear provision of information to

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to expect “*strong Treasury objections to any suggestion that a special compensation scheme should be set up for haemophiliacs*”. Memo from Roderick Toohar to Malcolm Harris 15 January 1987 DHSC0014947\_034

24 *The Northern Echo Sympathy, but no compensation* 4 February 1987 DHSC0004753\_071

25 Dr Moore became the deputy director of the National Directorate of the Blood Transfusion Service in his next role.

26 Brief from Dr Moore to C A Muir 26 February 1987 DHSC0001376

27 Attributed principally to Dr Smithies who was the medical officer with responsibility for blood and blood products: see evidence of Dr Moore addressing the briefing note. Dr Roger Moore Transcript 18 January 2022 pp90-91 INQY1000172

28 When asked whether there had been any investigation, inquiry or analysis within the Department of Health to see if anyone had been at fault, and whether what had happened was truly unavoidable or could have been avoided, Dr Moore gave an answer that suggested it was simply an assumption and that haemophilia centre directors “*had actually done their best to protect their patients*” who were “*given treatment in good faith*”. Dr Roger Moore Transcript 18 January 2022 pp90-92 INQY1000172

29 Memo from Dr Smithies to Malcolm Harris 17 February 1987 p3 DHSC0001383

patients about the risks so that they could give (or withhold) informed consent. The DHSS took no steps to determine whether this was in fact what had happened.

Also in February 1987 advice was sought on behalf of the Secretary of State, Norman Fowler, as to the possible liability of the NHS.<sup>30</sup> The advice received was that there was certainly potential for some breach of a duty of care on the part of health authorities, if there had been a failure to take all proper steps to guard against infection or a failure to get the informed consent of the patient undergoing treatment involving unpreventable risk.<sup>31</sup>

The Haemophilia Society then took the unusual step of publicly revealing the advice it had received from Counsel as to the prospect of such a claim succeeding.<sup>32</sup> The Society suggested that many individual claims might not succeed. The reasons for this were not, however, so much that no wrong had been done by the system as a whole, but that identifying the relevant wrongdoer within that system and proving negligence were problematic.<sup>33</sup> Its May 1987 *Haemofact* publication sought to make clear its “*unanimous and strong view*” that people with haemophilia who were HIV positive deserved special financial support from the Government. Irrespective of legal responsibility, it argued that the Government had a “*clear moral duty*” to provide recompense.<sup>34</sup> Meanwhile, Dr Smithies, attending the UKHCDO’s AIDS Group meeting on 11 May, responded to a question about compensation by saying that there was “*no government scheme at present nor were there any plans for setting up such a scheme. Patients who felt they had a case would have to apply for compensation through the courts.*”<sup>35</sup>

Professor Arthur Bloom wrote to the Chief Medical Officer (“CMO”), Sir Donald Acheson, in May 1987 raising the question of compensation; the CMO’s response recorded that compensation raised “*many difficult issues*” and that the subject was “*clearly outside the*

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30 Memo from Strachan Heppell to John Brockman 4 February 1987 DHSC0014947\_004

31 The memo said “*It is very difficult to cover possibilities in the abstract. I do not know for example the extent of involvement of the Department in control of the import of blood products from overseas which could result in some failure amounting to negligence on the part of the Department, but there would certainly be potential for some breach of a duty of care on the part of health authorities as bodies and of individual members of staff working for them. Whether a body or person in the NHS could be held liable in negligence would depend on whether, in the then state of medical and technical knowledge, there had been a failure to take all proper steps to guard against infection or – if it was known that there could be an unpreventable risk – to get the informed consent of the patient to undergoing treatment involving such risk. In deciding whether there had been a breach of a duty of care, the court, would have to consider all the circumstances and the state of informed medical opinion and scientific knowledge at the time.*” Memo from John Brockman to Strachan Heppell 6 February 1987 pp1-2 DHSC0014947\_027

32 See the chapter on the *Haemophilia Society*.

33 Haemophilia Society *Haemofact* No12 March 1987 STHB0000432. It does not appear to have discouraged the near 1,000 plaintiffs who brought what became known as the HIV litigation.

34 Haemophilia Society *Haemofact* No13 May 1987 HCDO0000279\_025

35 Minutes of AIDS Group of Haemophilia Centre Directors meeting 11 May 1987 p3 HCDO0000271\_044. At the meeting of reference centre directors on the same day, it was agreed that Dr Peter Jones should inform the Haemophilia Society that the reference centre directors fully supported the attempts to obtain “*some compensation for haemophiliacs infected with HIV as a consequence of transfusion therapy.*” Minutes of Haemophilia Reference Centre Directors meeting 11 May 1987 p2 HCDO0000424

*remit of EAGA*". He added that "*in my position as CMO I find that it would be inappropriate to select out a particular group of patients for particular support.*"<sup>36</sup>

The House of Commons' Social Services Committee had announced an enquiry into AIDS in November 1986 and as it neared the end of that process it heard on 13 May 1987 from the Secretary of State (Norman Fowler), the Minister of State (Tony Newton) and the CMO.<sup>37</sup> The question of compensation was addressed by Tony Newton. Whilst professing to be "*intensely sympathetic*", he suggested that it was very difficult to discern a basis to distinguish between "*medical treatment with blood products given in good faith and without negligence and medical treatment of any other kind that results in an injury or prolonged disabling condition ... there has never been a general state scheme in this country to compensate those who suffer the unavoidable adverse effects which may arise from some medical procedures.*"<sup>38</sup> The Committee's report, when published, noted the Government's position but suggested that "*Calls for compensation for haemophiliacs and others who have become HIV positive as a consequence of infected blood transfusions and for special life insurance arrangements for haemophiliacs deserve careful consideration.*"<sup>39</sup>

A press conference the following month – on 4 June 1987 – included a question about the treatment of people with haemophilia. The Prime Minister's response was "*The Government does not treat haemophiliacs; the doctors treat haemophiliacs!*". Asked why there was a refusal to provide compensation, Tony Newton reiterated that "*we see it very difficult to draw distinctions between people who experience, say, a tragic problem of this kind in this way when the treatment is on the best available knowledge and in good faith, and medical accidents that can occur in other ways.*"<sup>40</sup>

However, whilst he continued to maintain this line publicly, Tony Newton began to have doubts about the continued position against compensation in the summer of 1987. On 7 July 1987 a submission from Dr Roger Moore referred to the Haemophilia Society's campaign, which was expected to launch in September, and advised that in anticipation of increased pressure officials were examining ways of "*compensating haemophiliacs as a*

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36 Letter from Sir Donald Acheson to Professor Arthur Bloom 1 June 1987 USOT0000058\_024

37 A speaking note and background briefing were provided to Ministers in advance. Amongst other matters these listed the welfare benefits that people with haemophilia could claim. Briefing on Select Committee enquiry on AIDS: Secretary of State's oral evidence 7 May 1987 DHSC0006393\_018. The line to take was summarised as "*Greatest sympathy for those affected. It was not until knowledge grew, that safe blood products could be made and used. There has never been a general State scheme to compensate unavoidable, adverse effects from medical procedures. If negligence then can take action through courts.*" AIDS: Basic facts summary sheet 8 May 1987 p2 DHSC0006393\_019

38 Third Report from the House of Commons' Social Services Committee *Problems Associated with AIDS (Minutes of Evidence and Memoranda)* 13 May 1987 p62 WITN0771140. The same line was provided in a briefing to the CMO in June 1987 in anticipation of a visit that he was making to Newcastle. Briefing from Dr Smithies to Dr Lewis 12 June 1987 p7 DHSC0001381

39 The Committee added "*We are conscious however that demands for compensation raise many difficult issues which will need to be further considered in the future.*" Third Report from the House of Commons' Social Services Committee *Problems Associated with AIDS (Report and Proceedings)* 13 May 1987 p99 CBLA0002374

40 Press Conference *Pensions* 4 June 1987 p2 HMTR0005023

*special case.*<sup>41</sup> Ministers were asked to agree that this further look at the matter should be made public (a reply to Frank Dobson MP, who had been raising the issue, was proposed). In response the Secretary of State for Health and Social Services, John Moore, wrote “*This is very difficult. But my initial reaction is it would be most unwise to do’, (ie make the ‘further look’ at the haemophiliacs case public).*”<sup>42</sup>

Following a meeting between officials, Tony Newton, and the Parliamentary Under-Secretary of State for Health, Edwina Currie, on 15 July 1987, it was agreed that officials would provide a draft minute for Tony Newton to send to the Secretary of State seeking agreement to officials carrying out further work on possible options for compensation. The option favoured by Tony Newton and Edwina Currie was the idea of giving a sum of money to the Haemophilia Society to distribute as they thought best.<sup>43</sup>

On 26 August Tony Newton wrote to the Secretary of State that it was “*quite clear that we will be under considerable parliamentary and public pressure after the recess to do something for infected haemophiliacs ... It will be emotive and highly charged. I would expect it to attract considerable support on all sides of the House.*”<sup>44</sup> John Moore was unconvinced, responding that he felt that the present line against compensation should be maintained.<sup>45</sup>

It was against this background (but unaware of Tony Newton’s position) that in September 1987 the Haemophilia Society sought a meeting with the Secretary of State about compensation for people with haemophilia who had been infected with HIV, and launched a campaign. Pleading with the Government to stop “*prevaricating*” and to act swiftly, the Society wrote: “*The tragedy of twelve hundred people dying as a result of National Health Service treatment is a disaster in its own right. The Social and financial implications surrounding their infection and possible death place that disaster upon epic proportions. The Government is the only institution capable of minimising the distress of all those concerned.*”<sup>46</sup>

Officials thought that the media and many MPs would be sympathetic to their campaign, and recommended a meeting so that the Minister could demonstrate that he was personally aware of their case.<sup>47</sup> At this stage John Moore remained firm in his view that there should be no compensation, for the reasons which had thus far been advanced. He wrote to the Prime Minister on 24 September:

*“I have looked at the case for compensation again carefully in the light of the impending campaign but have concluded that the line taken with the Social Services Committee was right. Any special arrangements for compensation*

41 Submission from Dr Moore to Malcolm Harris and Jenny Harper 7 July 1987 p1 WITN0771206

42 Memo from Jane McKessack to Jenny Harper 15 July 1987 DHSC0002375\_024

43 Memo from Jenny Harper to Malcolm Harris 15 July 1987 DHSC0004541\_183. Edwina Currie Jones told the Inquiry that this was the route which she supported. Written Statement of Edwina Currie Jones para 6.2 WITN5287001

44 Memo from Tony Newton to the Secretary of State 26 August 1987 p1 DHSC0004541\_079

45 Memo from Flora Goldhill to Malcolm Harris 4 September 1987 WITN5287003

46 AIDS and Haemophilia – The Hidden Disaster 23 October 1987 p3 HSOC0004680

47 Memo from Dr Moore to Malcolm Harris and Flora Goldhill 23 September 1987 DHSC0004541\_145

*could cost a minimum of £3 million and could only be funded at the expense of other priorities. Moreover, it is logistically difficult to distinguish the claim by haemophiliacs from the claim of many others damaged in the course of their medical treatment. And there is no doubt that compensating haemophiliacs would lead to pressure from many other groups for similar treatment. While all of us must have every sympathy for haemophiliacs who have been infected with the HIV virus, I do not feel it would be wise to set a general precedent by accepting that the Government should provide a special compensation scheme.”<sup>48</sup>*

In October 1987, in advance of the meeting, the Haemophilia Society provided a submission to the Government. It recorded that of the 1,200 people understood to have been exposed to HIV from within the haemophilia community, to date 60 had been notified as having AIDS and 45 had died.<sup>49</sup> It described the intolerable financial, social and family burden, and asked for “*immediate, positive and compassionate government action.*”<sup>50</sup> And in anticipation of the meeting, *The Northern Echo* stepped up its campaign, sending a special campaigning supplement entitled *A Fight For Justice* to every MP.<sup>51</sup>

On 21 October 1987 Dr Smithies advised the CMO’s private secretary that in considering the consequences of a compensation scheme for people with haemophilia infected with HIV, account would need to be taken of the claims of recipients of HIV infected blood donations and organ transplants, and of the implications for people with haemophilia to whom non-A non-B Hepatitis had been transmitted (said to be “*in the region of 96-100% of those who have been treated with products made from plasma pools*”).<sup>52</sup>

At some point before the meeting with the Haemophilia Society, however, John Moore’s stance began to shift. On or around 30 October Tony Newton sent a minute to the Prime Minister<sup>53</sup> referring to John Moore’s minute of 24 September, but adding that “*Whilst John and I still consider those arguments to be intellectually valid, there is a powerful practical case for recognising the particular circumstances of the infected haemophiliacs.*” Referring to the “*very strong support*” for the Society’s campaign, “*particularly from our own supporters inside and outside the House*”, John Moore and Tony Newton had concluded that the line which had been taken was “*unlikely to prove politically sustainable.*” Their proposal was to tell the Society that the Government sympathised, was considering how best to respond,

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48 Memo from John Moore to the Prime Minister 24 September 1987 SCGV0000007\_050. Commenting on this document in her written statement, Edwina Currie Jones noted that John Moore’s note had been widely circulated and suggested that he was “*trying to shut down discussion on this topic.*” Written Statement of Edwina Currie Jones para 6.16 WITN5287001

49 Many more subsequently developed AIDS and died.

50 Haemophilia Society Submission on AIDS, Haemophilia and the Government October 1987 p4, p6 HSOC0003459

51 *The Northern Echo Echo steps up campaign* 2 November 1987 DHSC0004541\_027

52 Memo from Dr Smithies to Dr Gwyneth Lewis 21 October 1987 DHSC0004541\_111

53 In a possible sign that the Government’s stance was shifting, the Prime Minister had, on 27 October, responded to a question about the “*desperate plight of the haemophiliac AIDS victims*” by stating that she would discuss the matter with the Minister of State for Health, Tony Newton, rather than simply repeating the Government line. Hansard oral answer on People with Haemophilia and AIDS 27 October 1987 DHSC0004541\_082

and would talk to them again when a decision had been reached, and to discuss the options with colleagues in advance of a further meeting with the Society with the aim “to identify an acceptable response which runs the least risk of setting a precedent and keeps direct Government involvement to a minimum.”<sup>54</sup> The cost was thought to be likely to be of the order of £5-10 million.<sup>55</sup>

John Major, who was then Chief Secretary to the Treasury, advocated a more cautious approach. He responded to Tony Newton on 2 November, concerned about the precedent (“I do not feel that we can afford to offer such a response until the pros and cons have been thoroughly considered”) and recommending that they should “listen only at this stage” to the Society, “with no implication that the Government will take action.”<sup>56</sup> A handwritten note on a copy of Tony Newton’s minute stated “Prime Minister! This is a major about-turn. Content?”<sup>57</sup>

It is apparent that by the time of the meeting between John Moore, Tony Newton and the Society, the media pressure was intense. The advance briefing provided by Dr Roger Moore to the Secretary of State explained that:

*“The campaign was given a Press launch on 13 October. There will be a lobby of MP’s on 5 November, all MP’s have been sent campaign literature. So far over 170 pieces of Private Office correspondence on the issue have been received. More than 110 needing a Ministerial reply. Nearly all the quality newspapers have now carried articles or editorials supporting the campaign<sup>58</sup> ... The television programme ‘First Tuesday’ is expected to run the issue in December or January.”<sup>59</sup>*

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54 Minute from Tony Newton to the Prime Minister DHSC0002375\_010

55 This figure appears to have been arrived at following discussions between Tony Newton, the Parliamentary Under-Secretary of State and officials. Memo from Tony Newton to the Secretary of State 26 August 1987 DHSC0004541\_079

56 Letter from John Major to Tony Newton 2 November 1987 p1 CABO0100005\_003

57 Letter from John Major to Tony Newton 2 November 1987 p2 CABO0100005\_003. A minute from John O’Sullivan (an adviser in Number 10) to the Prime Minister on the same date expressed agreement with the drift of Tony Newton’s memorandum: “Refusing compensation would give us a damaging reputation for hard-hearted parsimony at the very time when we need public support for more selective spending on health and social security. Since there is widespread sympathy for the haemophiliacs, a refusal to compensate would be hard to sustain, so we would risk the worst of both worlds. And the sums involved are small.” Minute from John O’Sullivan to the Prime Minister 2 November 1987 CABO0100005\_005. The Prime Minister was content that the issue be reconsidered. Letter from Andy Bearpark to Flora Goldhill 2 November 1987 DHSC0004541\_108

58 On 14 October 1987, following the Society’s press launch, stories appeared in *The Times*, *Daily Telegraph*, *Guardian*, *Independent* and *Daily Mail*. *The Times Haemophiliacs urge fund for Aids sufferers*; *Daily Telegraph Haemophiliacs seek Aids disability pay after NHS infection*; *The Guardian Aids blood victims claim £30m from NHS*; *The Independent Aids kills 45 haemophiliacs*; *Daily Mail Eight people in one family are hit by AIDS* 14 October 1987 DHSC0004528\_038

59 Memo from Dr Moore to Malcolm Harris and Geoffrey Podger 30 October 1987 p5 DHSC0004528\_031. Notwithstanding the fact that ministers were apparently beginning to shift from the existing approach, the briefing repeated the existing lines to take, concluding with this suggested line “Although I do not believe further special financial measures can be justified, we will continue to show our sympathy in these practical ways.” The “practical ways” referred to the funds provided to haemophilia reference centres in England and Wales for counselling costs, the existence of social security benefits and the investment in the Blood Products Laboratory: “Last but not least we have provided the splendid new factory at Elstree.”



The meeting was on 3 November 1987.<sup>60</sup> In the words of Dr Moore, who was there: *“it was a very incredible meeting. I have been to thousands of meetings but that one is very clear in my mind.”*<sup>61</sup> The Society chair and its general secretary brought with them three young men who had contracted HIV from their blood products. What occurred is best described in the words of Dr Moore:

*“what struck us, actually, was that these were people who had a right to be angry and they weren’t; they were only concerned about the families that they would leave behind. And we listened and we were really moved. I mean, I don’t think I’ve ever seen a minister weep before but John Moore – – and we were totally, totally dumbfounded, really. And, anyway, the Haemophilia Society delegation left, and we sat round and it wasn’t a question of whether we do anything, it was, you know, what can we do? What actually can we do? And I’ve never really seen any meeting that’s kind of changed direction so quickly or to such great effect as that.”*<sup>62</sup>

This was a significant moment. Though the to-ing and fro-ing between ministers showed that the Government had slowly begun to reconsider its stance, after this it became clear that the die was cast: it had changed direction.

The very next day, on 4 November 1987, in a confidential memorandum, John Moore proposed to a Cabinet Sub-Committee that special financial assistance for people with haemophilia suffering from AIDS should be given.<sup>63</sup> The memorandum suggested that the people with haemophilia were *“mostly infected at a time when there was only a limited knowledge of the HIV virus and how it could be inactivated.”*<sup>64</sup> A lobby of MPs was due on the following day; the Haemophilia Society campaign enjoyed the backing of many Government supporters, and his memorandum said it was *“unlikely that we shall be able to sustain the present line.”* The *“present line”* was that (a) there was no difference in principle between those with haemophilia and others damaged in the course of their medical care; (b) there was no general scheme for compensating those so injured; (c) compensation was ordered by the courts only when negligence had been proved; and (d) the Government was already funding a number of voluntary agencies which provided advice and services to people with AIDS and people with haemophilia could be expected to derive some benefit from this. The memorandum noted that the Haemophilia Society had successfully got across their view that people with haemophilia’s problems with AIDS were due to the Government’s

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60 Memo from Dr Moore to Flora Goldhill 13 November 1987 p6 DHSC0002375\_052

61 Dr Roger Moore Transcript 18 January 2022 pp94-95 INQY1000172

62 Dr Roger Moore Transcript 18 January 2022 pp94-96 INQY1000172

63 The Sub-Committee on AIDS of the Cabinet’s Home and Social Affairs Committee, referred to as H(A). Memo from the Secretary of State for Social Services on special financial assistance for haemophiliacs 4 November 1987 CABO0100001\_002

64 The word used is *“mostly”*, which suggests that he did not exclude the possibility that some had been infected at a time when there was greater knowledge.

failure to ensure self-sufficiency in blood products. This was “*difficult to refute convincingly in presentational terms.*”<sup>65</sup> In conclusion he said:

*“The affected haemophiliacs form a distinct, identifiable and finite group, which makes it feasible to devise a one-off solution, which could be defended as a ‘special case’. Unlike others injured by their medical treatment, there is no doubt about causation or about the nature of the injury received. Nor should there be any increase in the number infected in this way. Furthermore, it should be noted that the vaccine damage payments scheme already breaches the coherence of the present position. It is the advice of DHSS lawyers that a scheme of financial help, in the form of an ex gratia payment would not imply any admission of legal liability by the Government or Health Authorities.”*<sup>66</sup>

He suggested that there were two options. The first was that the Government could directly pay a lump sum to each infected person with haemophilia, totalling £10 million apportioned as to £8,300 for each of the 1,200 infected people with haemophilia. The second was: “*to give a once and for all lump sum, of up to £10 million to the Haemophilia Society to administer and distribute to cases of need ... Payments would be made to haemophiliacs and dependents [sic], including wives infected by haemophiliac husbands.*”

This comment followed:

*“The second option is particularly attractive as it minimises Government intervention; and it would be consistent with the policy of not accepting any direct responsibility for damage caused in this way. The Haemophilia Society already administer a small hardship fund (financed by voluntary donations etc) and currently spending at a rate of £3,000 per month, mainly on those suffering from AIDS. They thus have experience in targeting relief to haemophiliacs and their families.”*<sup>67</sup>

The memorandum therefore proposed that special financial help should be given to people with haemophilia; that this should take the form of a grant of up to £10 million in 1987-88; that it should be funded from the contingency reserve; and that further work should be done on details of how it could be administered via the Haemophilia Society, and how such an initiative should be presented to avoid others seeking similar treatment by relying upon it as a precedent. The comment on the second option is marked by the Government’s apparent wish to minimise any intervention, and distance itself from any suggestion of accepting direct responsibility.

65 The full quote begins with the words: “*Whilst unfair [ie to the Government] this is difficult, etc.*” It should not be thought that on the basis of this quote the Government was itself convinced it had done wrong – it just thought it would be difficult to persuade others that this was the case.

66 Memo from the Secretary of State for Social Services on special financial assistance for haemophiliacs 4 November 1987 p3 CABO0100001\_002

67 Memo from the Secretary of State for Social Services on special financial assistance for haemophiliacs 4 November 1987 p4 CABO0100001\_002

The memorandum was considered by the Sub-Committee on AIDS on 10 November 1987. A briefing paper for the Lord President of the Privy Council (who chaired the Sub-Committee) advised that DHSS ministers had consistently resisted compensation; that a campaign had attracted a good deal of political and public support, such that the position was not sustainable unless concessions were made; and that *“The case for reversing the present line and singling out haemophiliacs for special compensation is essentially a political one.”* The proposed grant to the Society was *“not compensation – which could run to hundreds of thousands of pounds per person – but a gesture of limited financial assistance to meet particular needs.”* £10 million would be sufficient to provide an average payment of around £8,300 to each of those affected: *“This does not seem a great deal”*.<sup>68</sup>

Contributions to the discussion at the Sub-Committee meeting came from the Solicitor General, who advised that the courts would be unlikely to be influenced by the establishment of a scheme *“provided that the payments were presented expressly as ex gratia and that the announcement of the scheme was accompanied by an express disclaimer of liability”*; and from the Chief Secretary to the Treasury who acknowledged the *“very strong case”* for financial assistance but stressed that it was vital that the proposed scheme should be ring-fenced as tightly as possible. At the conclusion of the discussion there was agreement to the announcement of a sum of £10 million to be made available for administration by the Haemophilia Society.<sup>69</sup>

A statement to the House of Commons from Tony Newton followed on 16 November 1987. The Government proposed to make an ex gratia grant of £10 million to the Haemophilia Society to enable it to establish a special trust fund. The Society was to be *“able to make payments to the affected individuals and families throughout the United Kingdom, and to do so with greater flexibility than could readily be achieved in any other way.”* It noted that the Society had asked for *“advice and assistance in administering the fund, which [the Government had] gladly agreed to arrange.”*<sup>70</sup>

He told the House of Commons: *“This is not a compensation scheme. That must be made clear. It is a recognition of a special and unique combination of circumstances.”* The £10 million was: *“a broad estimate of a sum that we felt would give significant help to the group affected, recognising that to calculate in terms of a specific sum per individual would not take account of the great differences between the circumstances of the individuals*

68 The Lord President (of the Privy Council) was then William Whitelaw. Briefing paper from Anthony Langdon to the Lord President 6 November 1987 p2 CABO0000205. Emphasis in original.

69 Minutes of Home and Social Affairs Committee Sub-Committee on AIDS meeting 10 November 1987 p8, p10 CABO100016\_011. The Prime Minister was updated on 11 November 1987 and it was agreed by the full Cabinet on 12 November 1987. Letter from the Lord President’s Office to the Prime Minister 11 November 1987 DHSC0002375\_032, Minutes of Cabinet Office meeting 12 November 1987 p5 CABO0000185. On the question of ring-fencing, Edwina Currie Jones told the Inquiry that her view was and remains that the desire to avoid creating a precedent was *“something of a forlorn hope”* but that there was no harm in that as she supported the needs of individual groups being assessed on merit. Written Statement of Edwina Currie Jones para 6.37, para 6.55 WITN5287001

70 In the course of the debate Tony Newton added *“We believe that this is a proper sum, but of course we will not be closed to representations that might be made at a later stage.”* Hansard parliamentary debate on Haemophiliacs (Financial Assistance) 16 November 1987 p1, p4 LDOW0000241

*affected.*” It was up to the Haemophilia Society to decide how to administer the £10 million: it would “*not, in effect, be acting as the Government’s agent.*”<sup>71</sup>

Just over a week later, Strachan Heppell, a civil servant at the DHSS, met the chair and general secretary of the Haemophilia Society (Reverend Alan Tanner and David Watters, respectively).<sup>72</sup> They were assured that the administrative costs of the fund would not have to be paid from the fund or its income. Further discussions followed, which resulted in the Macfarlane Trust being set up as a body separate from the Haemophilia Society.<sup>73</sup>

## Commentary

Lord Fowler was asked whether there was any soul searching on the part of the DHSS to consider whether there had been any fault or wrongdoing by successive governments or anything that might have made the case for compensation stand out from others. This was his answer:

*“I would have thought that the case was that they regarded it as a pretty hopeless case to put forward, because you had the Chancellor of the Exchequer against you, you had the Prime Minister against you and you had most of the Cabinet against you, where on earth were you going to get a compensation scheme? You just weren’t.”*

He accepted that it was hopeless, not because it was unmeritorious, but because the political and financial commitment was not there and “*we were far too influenced by the argument ... which was if we give way on this, you’re giving way on an awful lot of other things.*”<sup>74</sup>

Lord Fowler was right that political and financial considerations underpinned the Government’s response in this initial period (and, as the following chapters of this Report demonstrate, continued to do so over the next three decades).

The Government plainly formed the view, at an early stage, that nothing had been done wrong, and that no financial assistance would be provided to people with bleeding disorders who had been infected with HIV. It did so without any proper investigation either into what had caused the infections or into the appalling plight of those infected. Had it done so this would have revealed systemic failures that contributed to what had occurred – the persistence with out-of-date, inadequate facilities for producing concentrates from domestic donations; a system of blood collection and distribution that was regionalised and fragmented; both leading to the importation of products from the US sourced from donors amongst whom transmissible disease was particularly prevalent<sup>75</sup> and known to be riskier; a lack of research

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71 Hansard parliamentary debate on Haemophiliacs (Financial Assistance) 16 November 1987 p1 LDOW0000241

72 Letter from Strachan Heppell to Reverend Tanner 2 December 1987 DHSC0003088\_008

73 The problems caused by the way in which the Trust was established following this and the details of how it operated over the following years are considered in the chapter on the *Macfarlane Trust*.

74 Lord Norman Fowler Transcript 22 September 2021 pp123-124 INQY1000145

75 By comparison with the UK.

into viral inactivation; a failure to see UK production as a whole, a joint effort between Scotland and England, as had originally been intended; coupled with a slow and inadequate response to taking precautions even when the writing was on the wall. To think of the infections as “*unavoidable adverse effects*” was a distortion of reality. Government fear of setting a precedent outweighed considerations of moral responsibility or compassion. The remarkable meeting of 3 November which led to John Moore’s tears showed a compassion which could change politics<sup>76</sup> – but it remains evident that it was largely public and political pressure which led to the change of position in November 1987.

The payment of £10 million to the Society, and through that route eventually into a charitable Trust, was a sum which would work out at roughly £8,300 per individual, even if only people who had been directly infected were considered. At that level, it was always likely to be seen as derisory. It was, as the briefing to the Lord President put it, a “*gesture*”.

One of the features of the Government’s payment was that it was a response to the particular needs of people with haemophilia who had been infected with HIV as a result of NHS treatment and those of their families and dependents. Yet no assessment of these needs was carried out. The history of the Macfarlane Trust shows how this approach proved short-sighted for government, insufficient for those it was intended to help, and actually hurtful to many.

What is also, and particularly, surprising is that there is very little evidence that once the Government knew of the dreadful consequences to which blood transfusions and blood products could lead, it asked what lessons could be learned from what had happened. It was its paramount duty to protect the nation’s health. There is scant evidence that it did anything to ensure that the like of what, by 1987, had just happened never happened again. In respect of Hepatitis C from transfusions and commercial blood products it was still happening: but little or nothing was done to address this. Rather, government preferred to assume that nothing had been done wrong and that, inferentially, there were no such lessons to be learned.

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76 It also showed the importance of government listening to members of the public who had lived experience.

## 6.2 HIV Haemophilia Litigation

This chapter looks at the Government’s response to the HIV haemophilia litigation and the process of settlement, including the lack of consultation with Scotland and “the waiver” which surrendered the plaintiffs’ rights to make claims in respect of hepatitis. It also considers the experiences of plaintiffs in that litigation, many of whom report a pressure to accept the terms of settlement.

### Key Dates

**1989** HIV haemophilia claims begin to be filed.

**June 1989** Submission to ministers says that “*at every stage*” the Government “*has acted as swiftly as possible to minimise the risk of infecting haemophiliacs with AIDS in light of the best expert opinion available at the time.*”

**November 1989** Decision to make further payment (£24 million) to the Macfarlane Trust.

**Late 1989 - 1990** Central defendants to the claims disclose many documents, but withhold others asserting public interest immunity (“PII”).

**26 June 1990** Mr Justice Ognall writes a letter to all parties, urging settlement.

**31 July 1990** Decision of the High Court about disclosure and PII, followed by a Court of Appeal ruling on 20 September 1990.

**9 November 1990** Settlement proposed on behalf of the plaintiffs (who are not aware).

**7 December 1990** William Waldegrave writes to the Prime Minister recommending settlement.

**11 December 1990** Prime Minister announces settlement in Parliament, which is how plaintiffs learn about it.

**May 1991** Settlement of claims in England and Wales. Agreement contains plaintiff waiver of future claims.

**June 1991** Settlement terms in respect of Scottish claims are finalised, without a similar waiver.

### People

**John Canavan** civil servant, Department of Health (1989 - 1994)

**Kenneth Clarke** Secretary of State for Health (1988 - 1990)

**Charles Dobson** senior civil servant, Department of Health

**Richard Gutowski** Medicines Control Agency (1983 - 1991)

**Strachan Heppell** senior civil servant, Department of Health

**Norman Lamont** Chief Secretary to the Treasury (1989 - 1990)

**David Mellor** Minister of State for Health (1988 - 1989), Chief Secretary to the Treasury (1990 - 1992)

**Sir Harry Ognall** Judge, HIV Haemophilia litigation

**Dr Hilary Pickles** principal medical officer (1988 - 1991)

**Dr Andrzej Rejman** senior medical officer, Department of Health (1989 - 1998)

**William Waldegrave** Secretary of State for Health (1990 - 1992)

**David Watters** general secretary, Haemophilia Society (1981 - 1994)

### Abbreviations

**CMO** Chief Medical Officer

**CSM** Committee on the Safety of Medicines

**Steering Committee** solicitors bringing the claims on a group footing

## Introduction

During 1989, a large number of individuals – in the end nearly 1,000 – brought claims against a large number of defendants in England and Wales. The “central defendants” as they were described in the action, were the Department of Health and the Welsh Office, the Licensing Authority established under the Medicines Act 1968, and the Committee on the Safety of Medicines (“CSM”). There were 220 further defendants consisting of all the regional health authorities, all the district health authorities, and certain special authorities including the Central Blood Laboratories Authority. This chapter focuses largely on the response of the central defendants. The fact that nearly 1,000 people with haemophilia chose the insecurities and stresses of litigation, in an effort to achieve recognition that they should not have been infected, shows the strength of their collective view. It is in itself a sad commentary on what had happened already that they thought that litigation was the only viable route to establish the facts; and although the focus of this chapter is on how the central defendants reacted, this should not be forgotten.

The chapter looks in detail at three principal areas concerning the litigation. First is the reaction of those in the Department of Health and Government to the litigation when it began; and a “line to take” being adopted that people received the best treatment in light of knowledge at the time. Second is the process of settlement: how it began, and from whom the initiative came: the Government or the litigants. Third is how it came about that the “waiver” was required when the claim was not for hepatitis but for HIV infection. In respect of both these last two, the position of litigants in Scotland and the absence of a waiver in Scotland both feature in the discussion.

The essential chronology of events is as follows:

1989	Litigation begins in England. <sup>77</sup>
1989-90	Defendants disclose many documents, but claim they are obliged to withhold others. The litigation is assigned to be heard by Mr Justice Ognall.
26 June 1990	After a preliminary hearing before him, Mr Justice Ognall writes a letter urging settlement.
31 July 1990	Another high court judge makes an order about the extent of disclosure which should be made. This is immediately appealed by both the defendants and the plaintiffs.
September 1990	Court of Appeal orders disclosure of most of the documents, and makes observations in passing about the nature of the claims.
December 1990	Moves to settle the claims begin.
1991	Terms of settlement of claims in England and Wales finalised.

<sup>77</sup> Although the expression England is used in the text, technically England and Wales share a common legal jurisdiction and the phrase “England and Wales” where used in the text of documents reflects this. It does not imply any separate consideration or input by the administration of government in Wales. By contrast, Scotland has had a separate legal jurisdiction since 1707.

May 1991	English claims settlement finally agreed. Contains a waiver, preventing a later claim in respect of infection with hepatitis as well as HIV.
June 1991	Settlement terms in respect of Scottish claims finalised. There is no waiver in respect of hepatitis.

## The HIV litigation in England and Wales

The litigation in England and Wales began in early 1989, with the issue of writs against a number of defendants. They were consolidated into a group action, against “the central defendants”. These included the Department of Health. The “plaintiffs” (as claimants used to be known) claimed that the duty of the state was such that if individuals could show that they were injured as a result of a failure to honour that duty they could claim monetary compensation against the state.

After a statement of claim had been issued, and defences entered from the central defendants, a next step in the litigation was the “discovery”<sup>78</sup> of relevant documents by both parties.

## Claim of public interest immunity

The Department of Health, the Licensing Authority and the CSM disclosed a number of documents. However, they listed a number (approximately 600) they did not disclose, beyond identifying that these were in classes of documents for which they claimed public interest immunity. The question of whether that claim could be upheld was raised before a High Court judge,<sup>79</sup> who on 31 July 1990 ordered the defendants to produce certain of those documents for which they had claimed immunity to be inspected by the court to see if, on a proper balance between the public interest in non-disclosure and the public interest in justice being done as between the parties, they should be disclosed.<sup>80</sup>

Both parties appealed: the plaintiffs seeking wider disclosure, the Department of Health seeking to reverse the order. The matter came before the Court of Appeal.<sup>81</sup> Judgment was given on 20 September 1990.

In the leading judgment, given by Lord Justice Ralph Gibson, he pointed out that the Department of Health had raised the matter of public interest immunity so as to prevent the disclosure of certain documents but:

*“The Department does not do that in order to put difficulty in the way of the plaintiffs, or to withhold from the court documents which might help the plaintiffs. The Department raises the matter because it is the duty of the Department in law to do so in support of the public interest in the proper functioning of the public*

78 In current terminology, this is “disclosure”.

79 Mr Justice Rougier.

80 *LPN36 v Bloomsbury Health Authority* 31 July 1990 pp24-25 CBLA0000001\_011

81 Consisting of Lord Justice Ralph Gibson, Lord Justice Thomas Bingham and Sir John Megaw.



*service, that is the executive arm of the government ... It is not for the Department but for the court to determine whether the documents should be produced. The plaintiffs acknowledge the validity of the claim to public interest immunity but ask the court to order production notwithstanding the existence of the valid claim to immunity. It is essential that that aspect of these proceedings should be clearly understood ... The task of the court is properly to balance the public interest in preserving the immunity on the one hand, and the public interest in the fair trial of the proceedings on the other” .<sup>82</sup>*

In short, there was nothing underhand or untoward in the approach of the Department of Health in seeking to keep some documents undisclosed: it was its obligation to take the immunity point, and for the court to decide if notwithstanding some public interest in immunity continuing, it was outbalanced by the public interest in justice being done in the litigation.

In the course of his judgment, Lord Justice Gibson said:

*“The plaintiffs have set out, in my judgment, a prima facie case to the effect that the Department knew or should have known of the risk to the plaintiffs from the use of concentrate obtained from suppliers in the United States; that practicable steps could have been taken by the Department to eliminate or to reduce that risk; and that if those steps had been taken the injury suffered by all or by some of the plaintiffs would not have been caused to them. By ‘prima facie case’ I mean no more than that the plaintiffs have alleged facts, which, if proved, could justify those conclusions ... No one could doubt the sincerity of the efforts of those in the Department to protect and to assist the plaintiffs as patients in the National Health Service, but on the pleaded case grave errors of judgment were made. Even if there was no grave error of judgment it appears to be not in dispute that there was in fact a failure to protect the plaintiffs from the danger of using blood products, whether imported or supplied in this country, which were infected ... If [the evidence or material available] support the conclusions which the plaintiffs say are to be derived from them, and in particular as to the knowledge which the Department had or should have had at the dates alleged of the nature and gravity of the risk to the plaintiffs, then ... It seems to me ... likely that ... failing to act appropriately upon available information, was the result of failure at some level within the Department to pass that available information to those who were required to make the decisions. If that is not in fact the explanation, but it is proved that the information as to the nature and gravity of the risk, and of the steps available to eliminate or reduce it, was supplied to those who were required to make the decisions then, in my judgment, the plaintiffs would have a prima facie case for asserting that the decisions were such that no reasonable or responsible person could properly make them.”<sup>83</sup>*

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82 *Re HIV Haemophilic Litigation* 20 September 1990 pp14-15 BPLL0016043\_025

83 *Re HIV Haemophilic Litigation* 20 September 1990 pp41-42 BPLL0016043\_025

He recognised that it all depended upon what was “*proved*”. In short, the case should proceed to trial; a judge should decide what facts were proved; and the judge should draw any conclusions as to whether in those circumstances a duty existed which, if broken, would entitle a person harmed as a result to receive recompense.

Lord Justice Bingham agreed in his judgment with what Lord Justice Gibson had said but added:

*“While there may be no very close precedent for the present claim, there has not perhaps, at least in this country, been any comparable calamity. Of the plaintiffs still living, the great majority have throughout their lives suffered the grave affliction of haemophilia. To this there has now been added the even graver affliction of AIDS, now or in the future. The tragedy was avoidable in the sense that, had different measures been taken in the 1970s and early 1980s, it could, at least in large measure, have been prevented ... If ... the plaintiffs can make good their factual allegations against the Department ... the law might arguably be thought defective if it did not afford redress.”*<sup>84</sup>

It is no part of this Inquiry’s function to determine matters of civil liability. It has no power to do so.<sup>85</sup> Nor is it any part of the function of the Inquiry to pass judgement on the legal merits of the arguments raised in the litigation.

For present purposes, given these observations by the Court of Appeal, it is sufficient to say that the case was not a hopeless one – whether viewed from the perspective of the plaintiffs or from the perspective of the defendants. It was a case in which (as it appears to me, in the light of experience) there were good arguments to be raised on both sides, and that neither success nor failure could be guaranteed. The point in mentioning that is to note that divergent views have been expressed since the case was settled. Some have expressed the view that the defendants were certain to lose, and therefore it was wrong for government to resist the claims, and government should be resented for this. Others have taken the position that the defence was certain to succeed, in which case there might be concern at the plaintiffs having been paid anything at all. Neither view is correct.

While recognising the necessity of testing the question of public interest immunity, the practical effect of it was twofold: first, it prolonged the litigation, because the claim of public interest immunity had first to be evaluated by a judge, and then there was an appeal to the Court of Appeal; second, it emphasised the power imbalance between the parties in terms of knowledge. There remained some categories of documents that would not be disclosed, and those documents that were to be produced were for inspection by the judge, for him then to determine if they should be disclosed to the plaintiffs.

84 *Re HIV Haemophilic Litigation* 20 September 1990 p57 BPLL0016043\_025. Sir John Megaw agreed with both judgments. *Re HIV Haemophilic Litigation* 20 September 1990 p60 BPLL0016043\_025. Accordingly, the view of the Court of Appeal was unanimous.

85 Section 2(1) of the Inquiries Act 2005 prohibits a public inquiry from ruling on or determining any person’s civil or criminal liability.

It would be wrong of me not to note the impact of this additional delay on the plaintiffs. They had only embarked on litigation because their efforts to obtain proper compensation – supported by the Haemophilia Society and a number of parliamentarians – had been consistently rebuffed by the Government. At that point facing a likely early and painful death, they were litigating because this seemed the only way they could secure some provision for their families.

## The litigation: early stages

At some stage during 1989 litigation began. Initially, individual actions were taken against the health authority or health board responsible for treating the plaintiff concerned. This became known by, and became a matter of concern to, haemophilia centre directors. “*Several weeks*” in advance of an extraordinary general meeting of haemophilia centre directors, which was called to discuss the coming litigation, a questionnaire was circulated by the United Kingdom Haemophilia Centre Directors’ Organisation (“UKHCDO”) to haemophilia centre directors. The results were reported at the meeting. At that stage 42 haemophilia centres were involved and 214 patients had taken legal action. Although the defendants to all actions were the relevant health authority or health board, action was also being taken against individual haemophilia centre directors, the Scottish National Blood Transfusion Service (“SNBTS”), the secretaries of state, the Department of Health and Social Security, the Licensing Authority, the CSM, and in one case the Attorney General and in another the drug company.<sup>86</sup>

This litigation was brought before the courts of England and Wales, which share the same legal system. Scotland has its own legal system, as does Northern Ireland. 12 cases involving people with haemophilia were instituted in Scotland.<sup>87</sup> The defenders<sup>88</sup> in Scotland were the relevant health board and the SNBTS. Detailed defences had been lodged for some of those 12 claims by the time the hearings before the Court of Appeal in England took place.<sup>89</sup> By October 1990 the number in Scotland had risen to 29 cases.<sup>90</sup>

Just two weeks before the statements of claim in the English and Welsh litigation were first lodged, David Watters of the Haemophilia Society wrote to Kenneth Clarke as Secretary of State for Health. He referred to preliminary hearings having started in the High Court. He wrote in support of the claims, but said that the £10 million which had been given to the Macfarlane Trust was simply not enough, and urged the Government “*to review the situation whereby those cases will have to drag themselves all the way through the Courts in a manner which will be both costly and deeply humiliating for both the litigants and the Government.*”<sup>91</sup>

86 Minutes of UKHCDO meeting 16 June 1989 pp1-2 PRSE0002656. The expression “*several weeks*” is taken from the records of this meeting.

87 Two of the people had AIDS and one had died by the time of the UKHCDO meeting.

88 The words “pursuer” and “defender” replace “plaintiff” (or “claimant”) and “defendant” in Scots practice.

89 Minutes of UKHCDO meeting 16 June 1989 p6 PRSE0002656

90 Letter from Pete Hancock to B D Connelly 26 October 1990 DHSC0020866\_114

91 Letter from David Watters to Kenneth Clarke 12 July 1989 p2 DHSC0002471\_065. By this time some 300 claims had been commenced in the High Court.

On 27 July 1989 the first of a number of versions of a statement of claim was served.<sup>92</sup> By then a number of solicitors including Mallen and Walton, Pannone Napier and J Keith Park & Co had combined to bring the claims on a co-ordinated, group footing. The claims were managed by a steering committee of representatives of those involved.

## Government reaction to the claims

In October 1989 there were discussions internally within the Department of Health about whether the litigation should be settled. Richard Gutowski was then working at the Medicines Control Agency.<sup>93</sup> He sent a fax to Mike Arthur seeking to resist any form of settlement, because to settle implied an admission of liability and risked encouraging further litigation and public pressure for similar settlements out of court. He said:

*“Whilst there may be unique features in the case of HIV officials do not think that any out of court settlement in that issue could be effectively ring fenced so as not to create a precedent. Any such settlement would need to involve the Licensing Authority and the CSM – it could not just include the Secretary of State in respect of his NHS responsibilities. It would accordingly be a precedent for similar out of court settlement of other claims against the Licensing Authority and CSM. It would also be likely to encourage further litigation against the Authority, which would be damaging to the integrity of the licensing system. It could lead on to over-defensive licensing decisions and reluctance of academics to serve on CSM and other S4 advisory committees, on which the Licensing Authority is reliant.”<sup>94</sup>*

By early March 1989 it was already known that a number of people with haemophilia who had been infected had begun claims. The first reaction, understandably, was to assess the likely strength of the claims. To that end, the Department of Health solicitors set out the pros and cons of orchestrating a combined defence to the litigation and suggesting where the balance of advantage lay. John Canavan, a civil servant in the Department of Health, recorded that the departmental information about the cases was very sketchy at that stage. It was not possible to say what the line of defence would be or to assess its strength.<sup>95</sup>

By 15 June 1989 matters had become clearer. A group action<sup>96</sup> was contemplated by the plaintiffs. It was at that stage that the Department of Health informed ministers. A first draft of a submission was prepared by the civil servant principally concerned in handling the

92 The Main Statement of Claim re: HIV Haemophiliacs Litigation 27 July 1989 OXUH0000002\_038

93 Richard Gutowski later became the team leader of the Department of Health’s blood policy team. Written Statement of Richard Gutowski paras 8-9 WITN5292001

94 Fax from Richard Gutowski to Mike Arthur p2 DHSC0006484\_009. Mike Arthur was a higher executive officer working with John Canavan in the section responsible for policy about blood supply and blood safety. Written Statement of John Canavan para 1.5 WITN7115001. “S4 advisory committees” refers to the committees established under section 4 of the Medicines Act 1968.

95 Memo from John Canavan to Charles Dobson and Graham Hart 16 March 1989 MHRA0017673

96 Where a number of individuals have individual claims in which there are significant common issues of fact or law it saves resources, and better serves justice, that such issues be determined, and any issues which are purely individual (such as, but not necessarily limited to, the calculation of compensation) left to be resolved later if by then they arise at all.

litigation (Charles Dobson, to whom John Canavan reported) with input from senior officials including the Chief Medical Officer (“CMO”) and junior counsel, and was copied widely within the department. A meeting with counsel was scheduled for 21 June, and it was known there was to be a court hearing on 29 June. Matters were urgent. It was sent to the Parliamentary Under-Secretary of State for Health (Roger Freeman), seeking Ministers’ views on resisting the case proceeding by group action rather than as a series of individual cases. It also sought Ministers’ views on *“other options for handling the litigation and the controversy which it is likely to engender.”*<sup>97</sup>

An expanded submission, following the legal meeting of 21 June, was sent to the Minister of State for Health, David Mellor, on 26 June. It had the same focus on immediate procedural steps (the court hearing at which the issue of group litigation would be raised was imminent) and also sought Ministers’ views on the question of *“ultimate liability”* raised by counsel. In the background information in both the submissions of 15 and 26 June, it was said: *“We believe that the government has a fair chance of successfully defending its role, given that at every stage it has acted as swiftly as possible to minimise the risk of infecting haemophiliacs with AIDS in the light of the best expert opinion available at the time.”*<sup>98</sup>

## Department of Health: line to take

Though the litigation raised difficult questions of law, this statement of belief contained an assertion of fact. Dr Andrzej Rejman, then a senior medical officer within the Department of Health, was asked during his oral evidence to the Inquiry whether he knew what *“enquiries or investigations or information the Department had in 1989 upon which to base such a confident assertion of everything having been done, essentially, as well and as quickly as possible.”*<sup>99</sup> In a lengthy answer Dr Rejman said that *“to a large extent, I suspect this was based on ... earlier considerations in 1988 and early ‘89”* which is when he thought that people within the Department of Health and legal advisers and counsel would have been starting to consider whether there were matters upon which the Department of Health might be liable.

He then said: *“I think Charles Dobson is basically saying ‘Look, we’ve spoken to counsel and counsel has said that, overall, he thinks that the case is – – can be defended on the basis that people actually did their best at the time with the knowledge they had at that time.’ ... And the expert opinion would presumably have been opinion they got primarily from the UKHCDO, who were the experts in the field”*.<sup>100</sup> In short, Dr Rejman himself did not know:

97 Memo from Charles Dobson to Strachan Heppell and Meg Kirk 15 June 1989 pp1-2 DHSC0003849\_114

98 Memo from Charles Dobson to Strachan Heppell and Meg Kirk 15 June 1989 p3 DHSC0003849\_114, Memo from Charles Dobson to Alan Davey 26 June 1989 p3 MHRA0017681

99 Dr Andrzej Rejman Transcript 10 May 2022 p99 INQY1000203. Dr Rejman was a senior medical officer in the Department of Health from March 1989 to December 1998. Dr Andrzej Rejman Transcript 10 May 2022 p19 INQY1000203

100 Dr Andrzej Rejman Transcript 10 May 2022 pp99-100 INQY1000203. John Canavan reported to Charles Dobson, who was the Assistant Secretary. Written Statement of John Canavan para 1.8 WITN7115001

he assumed it was the case, rather than having taken any steps himself to check; and the answers to the questions which followed in his evidence to the Inquiry immediately showed that so far as he knew the Department of Health had never itself gone through all the papers to inform an opinion.

When John Canavan was asked about the same phrase during his oral evidence there was an exchange as follows:

*“Q: Now, Mr Canavan, that sentence contains a positive assertion of what the Government has done and a positive assertion about the quality of expert opinion available to it. Would you agree that for that kind of assertion to be made to ministers, civil servants should have a proper factual basis for being able to say that in those terms?”*

*A: Yes.*

*Q: Do you know what enquiries or investigations or fact finding had been undertaken by mid-June 1989 to enable Mr Dobson to make that confident assertion?”*

*A: Well, probably by then he would have had a chance to read the background papers and his submission was probably passed round a number of colleagues before it went up ...*

*Q: As far as you can recall, had you at this stage, so we’re talking in the sort of first few months – – the first half of 1989, had you been involved yourself in any examination of the Department’s past actions, the Government’s actions, the advice available to it?”*

*A: I cannot really recall that I had” .<sup>101</sup>*

Shortly after that, John Canavan was asked in evidence about the Government’s approach to expert evidence, seeking to know whether what the Department of Health wanted was expert evidence supporting the Department’s case as opposed to “warts and all” expert evidence which might criticise the Department’s position. He answered: *“I think we were expecting that some of the experts would have critical comments to make.”<sup>102</sup>*

It is difficult to reconcile the statement of perfection in the submission put to ministers, without qualification, with the statement that the Department of Health **expected** that some experts would be critical. It is also surprising that the initial reaction, which was to assess the strength of the claims, had not resulted in a more nuanced response, based on documents and some evidence.

Dr Hilary Pickles, who was principal medical officer in the Med SEB<sup>103</sup> branch of the Department between March 1988 and June 1991, was so confident in the correctness of the defence that she felt there had been no negligence by the central defendants and those

101 John Canavan Transcript 22 September 2022 pp86-87 INQY1000244. He added that there was a chance that he might have been looking at *“what were the issues that needed to be addressed.”*

102 John Canavan Transcript 22 September 2022 p107 INQY1000244

103 Scientific Services, Equipment and Building Division

advising them such that, when it came to the prospect of settlement, she was unhappy about it.<sup>104</sup> Nonetheless, when asked about the same phrase as Dr Rejman and John Canavan had considered, whether there would need to have been some sort of factual assessment of what it was the Department of Health had done, what evidence and advice had been available to it before making such an assertion to ministers, there followed this exchange:

*“Q: But is this right, you don’t know what the factual basis for that confident assertion was?”*

*A: Well, you say factual basis. I mean, I didn’t have time to go back through all the historical records that were there when I started in AIDS.”*<sup>105</sup>

By way of comment, the evidence of the three people who gave evidence orally about this phrase in the submission showed, therefore, that none actually knew whether it was accurate.<sup>106</sup> None was aware of anyone having taken any steps to check that it was the case.

However, it must not be thought that Charles Dobson drafted the submissions without input from others: the first had been widely circulated, and there is no record that any exception was taken to the phrase. The focus may have been on the tactical issues with which the memo was centrally concerned. The second had been seen by a senior official (Strachan Heppell) and the CMO, amongst others.<sup>107</sup> No one queried the basis for the assertion.

The statement given to ministers, which asserted that *“at every stage it [the government] has acted as quickly as possible to minimise the risk of infecting haemophiliacs with AIDS in the light of the best expert opinion available at the time”*,<sup>108</sup> foreshadowed the similar view, repeated both at this time and later, that patients had had the best available treatment in the light of medical knowledge at the time.<sup>109</sup> Both statements make bold claims. There was agreement in evidence that any such claim, as to fact, should be based upon a solid

104 *“If there is said to be a risk of losing which is sufficient to justify a settlement, then either the case is weak because there was negligence or the judge and legal system biased, yet neither of these reasons are ones we could/should use.”* Memo from Dr Pickles to Chief Medical Officer 5 December 1990 DHSC0004365\_015. Dr Rejman reported to Dr Pickles. Written Statement of John Canavan para 1.7 WITN7115001

105 Dr Hilary Pickles Transcript 12 May 2022 p107 INQY1000205

106 Dr Pickles, Dr Rejman and John Canavan were each copied into the submission. Memo from Charles Dobson to Alan Davey 26 June 1989 p1 MHRA0017681

107 The CMO expressed the view some 18 months later (7 December 1990), at the time that it had been decided to accept proposals to settle the claims that *“he is satisfied that since the emergence of this problem in 1983 the advice given by medical and scientific staff of the Department of Health to Ministers has been both correct and timely bearing in mind the state of knowledge at the time and that there has been no negligence in relation to this advice. CMO feels that Mr Dobson’s submission to Secretary of State makes this point”* but this was in relation to a memo which Mr Dobson had sent two days beforehand, in which he had discussed the risk that a settlement might imply *“a degree of acceptance of liability for negligence.”* Memo from Jane Verity to Dr Hilary Pickles 7 December 1990 DHSC0046939\_009, Memo from Mr Dobson to Mr Alcock 5 December 1990 DHSC0003383\_006. This view of the CMO relates to the actions of civil servants when giving advice rather than being a view as to the quality of the treatment given at the time.

108 Memo from Charles Dobson to Alan Davey 26 June 1989 p3 MHRA0017681

109 Briefing for meeting between the Prime Minister and Robert Key and Haemophilia Society Deputation p3 DHSC0003989\_043, Letter from Paul Gray to Alan Davey 22 November 1989 p2 DHSC0002536\_031, Hansard extract – Speech by Robin Cook 6 March 1990 p4 BNOR0000359. See the discussion of this “line to take” elsewhere in this Report.

foundation of evidence. Yet it is difficult to avoid the conclusion that civil servants who, honestly but uncritically, adopted the phrase had no knowledge of any particular fact finding that had led to it. In essence, they relied upon the opinions of others, without knowing what they might be based upon.

A departmental view appears to have arisen. It was strong. It is difficult to resist the conclusion that it owed more to a sense that the Department of Health was defending the position of those who had worked in the health service and in government,<sup>110</sup> and that this statement was what they would prefer to believe rather than having any clear factual basis for doing so. On the face of it, it is not only a bold but an astonishing claim that over 1,000 people had been treated with blood products and had contracted HIV as a result, and that a number of people had been given transfusions and had contracted HIV as a result, and yet that they had had the best available treatment at the time, and that government had done everything it could, as quickly as possible, to avoid what happened. It could have been so, but the idea is so counter-intuitive that asserting that it was indeed so required careful and critical examination of the available factual material.

The very fact that it was “*expected*” within the Department of Health that a number of experts who might be approached would be critical of the Department of Health (as John Canavan’s answer shows)<sup>111</sup> suggests that people within the Department of Health who echoed the statement were nonetheless aware that it could, legitimately, be said that government had fallen short in its efforts to protect its public. It seems that, even knowing this, the statement was made without any qualification, or even a suggestion that there might be another, legitimate view, and that this was done without any further (or indeed any) investigation to check the facts. If the statement of belief were true, this should mean that there would be no prospect of liability being established, even if the significant legal difficulties in the way of the claims that had been brought were resolved in favour of the plaintiffs.

There is a significant contrast between these confident assertions of blamelessness and a view expressed to the Treasury when the question of liability and settlement were discussed in November 1990. A confidential note to the Chief Secretary to the Treasury, copied to the Permanent Secretary, said that: “*I understand from DH that there are more than 500*

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110 When expressing her views on the prospect of settlement in December 1990, Dr Pickles asked the CMO for reassurance that he “*would be acting to minimise the impact on the reputation of those individuals who were most involved (Dr E Harris, Dr D Walford and Dr A Smithies as well as yourself for the Department, all past CSM members and haemophilia specialists).*” Memo from Dr Pickles to CMO 5 December 1990 DHSC0004365\_015. Charles Dobson, in his June 1989 submission to ministers, suggested that “*proposals for positive publicity for the government’s position should be submitted*”. Memo from Charles Dobson to Alan Davey 26 June 1989 p7 MHRA0017681

111 Indeed, some were, notably Professor Geoffrey Rose who was professor of epidemiology at the London School of Hygiene and Tropical Medicine. Opinion of Professor Geoffrey Rose in *Haemophilia Group v Department of Health* MHRA0017604. Professor Rose’s views included that the Department of Health “*failed to move as vigorously and as efficiently as they should in order to increase the UK supplies*”, and that more could have been obtained from Scotland; that a substantially greater move to self-sufficiency would have been possible, leading probably to a reduction in the number of HIV infections; that the “*no conclusive proof*” line was “*technically correct, but it indicated a fallacious approach to policy. Evidence is never beyond question, and policy decisions should never demand proof*”. Opinion of Professor Geoffrey Rose in *Haemophilia Group v Department of Health* p2 MHRA0017604



*sufferers who might in principle have contracted the virus after the stage at which hospitals might reasonably have been expected to use different forms of treatment, even though there must be a very high probability that the vast majority of these cases would have contracted the virus well before that point.*<sup>112</sup>

This understanding of the Department of Health's analysis appears to have been the view taken by their legal advisors, rather than by policy officials or medical advisors. The legal advisors thought that there were some 20-30 cases where medical negligence was likely to be established, and up to 500 more where infection was likely to have occurred at the end of 1984 or in 1985.<sup>113</sup> Nonetheless, this view, which is attributed to the Department of Health, is inconsistent with the line that *"at every stage it [the government] has acted as swiftly as possible to minimise the risk of infecting haemophiliacs with AIDS in the light of the best expert opinion available at the time."*<sup>114</sup>

This reported view of the Department of Health also calls into question whether the line that was thereafter adopted in a number of ministerial pronouncements, reflecting the briefings the ministers had received, that there was no basis for a public inquiry, nor for compensation, because patients had received *"the best available treatment in the light of medical knowledge at the time"*, was justified by any adequate evaluation of the facts.<sup>115</sup>

## Early thinking on settlement

There may be many reasons why a court case will settle. Few, if any, cases are entirely without risk of losing. It may, often rightly, be said that the point at which to settle a case in which compensation is sought is the point at which the chances of getting more are balanced by the risks of getting less (or vice versa so far as the defendant/defender is concerned). Many people want to settle for reasons of cost, funding, delay, stress, fear of publicity, or because they think their point will have been made by some payment, even if it is not as much as they would like. In the case of group claims, the position is even more difficult: for members of a group may each have their own particular objects to achieve, yet each claim is technically a separate claim though aspects of it will be common to other claims, making it convenient, sensible and just that those aspects should be heard together at one and the same time.

Many of these issues were at play in respect of the HIV litigation. For instance, it was commonly thought that many of the plaintiffs would not live for long. That may have made speed, and the certainty which comes with a settlement (which, if agreed, is hardly ever the subject of appeal, with its onward delays) more important than in most cases. Recognition that a wrong may have been done was important, too, most particularly because it would help to counter some of the effects of stigma plaintiffs had suffered. Instead of vilification by

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112 Memo from Andrew Edwards to PS/Chief Secretary 26 November 1990 p3 HMTR0000002\_009

113 Memo from Andrew Edwards to Chief Secretary 29 November 1990 pp3-4 HMTR0000002\_011

114 Memo from Charles Dobson to Alan Davey 26 June 1989 p3 MHRA0017681

115 These matters are explored elsewhere in this Report.

much of the public, there would be recognition that wrongs had been done to them, and that they were blameless.

For the defendants, too, there would be a mix of motives: haemophilia centre directors recognised that plaintiffs who were being treated by their centres often blamed them for failures which had led to their illness. Yet, as people with bleeding disorders, they continued to require treatment. To cast such doctors as the defendants to legal claims brought by their patients made it exceptionally difficult, both for the plaintiffs to accept the treatment being offered, and for doctors to continue to provide treatment to people who were suing them. Government, and health authorities, were always likely to be worried about whether any acceptance even that the plaintiffs' case was arguable, so as to lead to a settlement, would encourage other patients in different circumstances, who felt wronged by the way they had been treated, to take group action against health authorities or the Department of Health.

The positions taken from time to time during the course of the HIV litigation demonstrate many of these aspects. It would be simplistic to think that in this case settlement was simply a question of whether the facts were sufficiently strong in favour of the plaintiffs for the defendants to wish to make a payment in respect of them, or the legal arguments for the defendant so strong that the plaintiffs would wish to secure what they could against the risks that they would lose whatever chance they had of receiving anything.

There was a desire within members of the UKHCDO for the Government to provide compensation. This came to the attention of Dr Rejman, who was the main conduit between UKHCDO and the Department of Health. His view was that at meetings directors pushed for the Department of Health to seek a settlement.<sup>116</sup> The press, too, were sympathetic to the claims.<sup>117</sup>

By 16 October 1989 Charles Dobson reported to his colleagues within the Department of Health dealing with the litigation that:

*“There are growing signs that ministers are becoming increasingly uneasy at the current advice from officials that, on balance, the government should resist the claim of HIV-infected haemophiliacs and if necessary fight it out in court. For instance, MS(H) has on two occasions asked for briefing on articles in the Sunday Times, and, on the most recent occasion, has asked for ‘advice as to whether there is any case for changing the basis for funding the Macfarland Trust [sic] – if we can find any money for ‘topping up’. MS(H) also ‘feels that the Department will lose on this whatever the outcome of the court case and would like to see what more can be done’.”*<sup>118</sup>

116 In his evidence to the Inquiry he said: *“they applied pressure in a sense that they had a go at me when I went to their meetings, and they said, ‘Look, you know, we really want you to finish off with this litigation, you know, it’s not only detracting’ – – I mean to say ... Professor Kernoff ... when he talks about detracting from patient care, I think he could also have said, ‘And also stop them litigating against us’, because a number of haemophilia doctors were being sued individually.”*  
Dr Andrzej Rejman Transcript 10 May 2022 pp88-89 INQY1000203

117 The Sunday Times *Blood money: the battle for justice* 1 October 1989 DHSC0046937\_132

118 Memo from Charles Dobson to Dr Pickles and others 16 October 1989 DHSC0006279\_025

This suggested to him that there should be a review as to the position that had been reached on the AIDS litigation front and “*to consider what options could be offered to ministers if they were minded to be more responsive to the haemophiliacs’ case (eg an out-of-court settlement which did not require HIV-infected sufferers to demonstrate financial need); and to consider how any such relaxation could be presented in the most favourable way.*”<sup>119</sup>

Accordingly, on 26 October 1989 Charles Dobson submitted a paper to the private office of the Minister of State. It reviewed the position on the litigation and on the Macfarlane Trust, and in a separate part considered options for making more money available to “*the haemophiliacs*”. The five options were:

- (a) an out-of-court settlement
- (b) increasing the Macfarlane Trust funds
- (c) making an ex gratia payment
- (d) establishing a commission of enquiry<sup>120</sup>
- (e) publicising the Government’s position, by responding to the “*allegations and misinformation contained in the Sunday Times campaign*” for example with “*a parallel history of the facts*” forming the basis of a press release.<sup>121</sup>

In his covering note, Charles Dobson described none of the options as being “*without difficulty*” explaining:

*“the cheaper ones are unlikely to buy much peace, and the more expensive ones run a severe risk of knock-on effects (eg on other litigation against the licensing authority, or of setting a precedent which would encourage other victims of medical accidents). And it is likely that the Treasury would resist any additional expenditure so long as Counsel advises that we have a good chance of winning the case. Our advice therefore remains that ministers should continue with the litigation and should not signal any readiness to provide additional funding, beyond the steps already in hand to allow greater flexibility to the Trust (and a veiled promise to consider topping up when it is needed). Ministers are also invited to consider the possibility of responding to the more inaccurate newspaper comments, so far as this is possible or advisable now that the case is before the courts.”*<sup>122</sup>

At this stage, Kenneth Clarke who was by now the Secretary of State for Health wrote to the Prime Minister, then Margaret Thatcher, about the campaign in the press being run on

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119 Memo from Charles Dobson to Dr Pickles and others 16 October 1989 DHSC0006279\_025. Emphasis in the original.

120 Essentially an inquiry such as is now known as a public inquiry, but then established under different authority.

121 Memo from Charles Dobson to Alan Davey 26 October 1989 DHSC0002536\_078, Report on HIV/ Haemophilia Litigation by HS1 October 1989 p10 DHSC0002536\_079

122 Memo from Charles Dobson to Alan Davey 26 October 1989 DHSC0002536\_078. Emphasis in the original.

behalf of people with haemophilia. He referred to the litigation. He asserted that there was no negligence on the part of the clinicians involved or on the part of the Government, expressed the view that the court would find in favour of the defendants, and was “*strongly of the view that the case should go to trial, and that we should not take any action that implied an admission of fault.*”<sup>123</sup> Though it had been suggested that an out-of-court settlement should be reached he was against this on two grounds: first there would be an implication that liability had been accepted which would have implications for NHS treatment generally, and secondly the cost consequences would be “*enormous*”. The “*real cost*”, including knock-on effects, would be unquantifiable. He went on to describe how reaching a settlement with this particular group of plaintiffs would represent a precedent for others. However, in light of the degree of public sympathy aroused by the campaign he suggested, and secured her approval to, a further allocation of £20 million.<sup>124</sup> (In the result, it was some £24 million to provide £20,000 each to 1,200 people with haemophilia).<sup>125</sup>

The option of paying additional funds to the Macfarlane Trust was therefore taken.

It was thus that on 23 November 1989 it was announced that additional monies would be made available to the Macfarlane Trust to enable each person with haemophilia who was registered with the Trust to receive £20,000.<sup>126</sup>

It was reported by Kate Lee, a solicitor acting for the central defendants, that counsel had then considered the possibility of sending a letter informing the plaintiffs that if they discontinued against the defendants the Government would forgo its own costs. It was suggested that, viewed with the additional money being made available to the Macfarlane Trust, this “*may be seen as a sympathetic gesture.*”<sup>127</sup> Richard Gutowski expressed unease about writing a similar letter, because: “*such an action could be construed as being overly aggressive. It could be argued that having given the Plaintiffs an additional ex-gratia payment the Government were now squeezing for the action to be discontinued especially as the payment was outside the litigation ie that the Government was buying itself out of the litigation.*”<sup>128</sup> On the same date Charles Dobson wrote and accepted this point: an open

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123 Letter from Kenneth Clarke to Prime Minister 17 November 1989 p1 HMTR0000001\_006, Lord Kenneth Clarke Transcript 28 July 2021 pp147-148 INQY1000142

124 Letter from Kenneth Clarke to Prime Minister 17 November 1989 HMTR0000001\_006. Following his letter, they discussed the proposal with the Chief Secretary and Attorney General and agreed that he would make an announcement after her meeting with backbenchers, including the Father of the House Sir Bernard Braine MP and the vice-chairman of the 1922 Committee Sir Geoffrey Johnson-Smith, scheduled for 22 November 1989. Letter from Paul Gray to Andrew McKeon 20 November 1989 HMTR0000001\_012. The meeting with the Parliamentary delegation ended with a brief discussion of the line for the MPs to use with the press: “*they understood the Government was now reflecting sympathetically on what had been said.*” Letter from Paul Gray to Alan Davey 22 November 1989 p3 DHSC0002536\_031. Kenneth Clarke discussed the matter again with the Prime Minister and the non-discretionary payments were increased from £10,000 to £20,000 within an unchanged overall allocation of £20 million. This was confirmed by the Chief Secretary to the Treasury. Memo to Prime Minister 22 November 1989 CABO0100002\_008, Letter from Norman Lamont to Kenneth Clarke 23 November 1989 DHSC0002536\_032

125 Minutes of Macfarlane Trust Trustees meeting 22 March 1990 p3 MACF0000002\_022

126 Hansard written answers on AIDS and Haemophiliacs 23 November 1989 HMTR0000001\_023

127 Memo from Kate Lee to Clive Wilson 7 December 1989 DHSC0044644

128 Memo from Richard Gutowski to Kate Lee 12 December 1989 WITN5292082

letter warning the plaintiffs about the costs of proceeding could too easily be misinterpreted by the press and this course was therefore seen as being “*politically unacceptable*.” Charles Dobson said he had consulted with Dr Pickles and Dr Rejman before expressing that view.<sup>129</sup>

## Letter from Mr Justice Ognall June 1990

Mr Justice Harry Ognall was the assigned judge. The case was due to be heard in March 1991, but the judge had charge of procedural issues which arose before that in preparation for trial. Having considered these issues at a preliminary stage, he then took the unusual step of writing to the parties to set out his view that compromise of the action was desirable because it was “*cardinally important*” that people should not die before knowing the outcome of the litigation.<sup>130</sup>

The letter read as follows in its material parts:

*“It is rare that I take an initiative of this kind in civil litigation before me. But the circumstances of these actions are such that I have no hesitation in doing so, and in much more specific terms that might normally be expected or considered appropriate.*

*Now that the issues have been clarified by the pleadings, I wish to invite the parties to give anxious consideration to the prospects of any compromise of these proceedings. If consideration is already being given, I would like to think that these observations will lend impetus to it.*

*So far as the Plaintiffs are concerned they, no doubt, recognise the legal difficulties attending the argument as to the nature and extent of the alleged duty of care and its breach. Likewise, with regard to the issue as to whether any proven breach of duty is capable of giving rise to any individual cause of action by an injured party. The Plaintiffs advisors have no doubt also taken account of the issue as to causation in each individual case.*

*There must also be, I suppose, unusually large areas of uncertainty attendant upon assessment of quantum.*

*But when all those factors are taken into account, it seems to me that for a number of reasons, it is not an abuse of language to describe these actions as unique in their surrounding circumstances. I hope that I will be allowed to identify some of those circumstances.*

*A government which takes upon itself the role of public provider of medical advice and clinical services is in a very different position to any commercial organisation. It is clearly arguable that their duty to innocent citizens who suffer injury under the aegis of such treatment has a moral dimension to it which should distinguish their assessment of their position from that criteria to be adopted by other defendants*

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129 Memo from Charles Dobson to Clive Wilson 12 December 1989 DHSC0046948\_058

130 Letter from Sir Harry Ognall 26 June 1990 p2 DHSC0046964\_024

*of a corporate character. Government owes a duty under this to its shareholders or insurers. It should also mean that the public may be entitled to expect from government an appraisal of their position which is not confined solely to legal principles to be found in the law of negligence, or problems of proof.”*<sup>131</sup>

He went on to say that compromise did not necessarily mean any admission of blameworthiness. He drew attention to the plight of the plaintiffs, or many of them, as a “*special one*”: that they lived in the shadow of a fatal condition for which there was presently no known cure; that many might die without knowing the outcome of the litigation; that it might well be the end of 1991 before the legal process had been exhausted; and that it was common ground that all the plaintiffs were entirely blameless. In the event of the plaintiffs succeeding, it might then be necessary to take further time to set “*benchmarks*” for quantum. He added:

*“It might be said that I have raised consideration of a political rather than a purely legal character. I acknowledge that. But I believe that the legal profession has a duty to do its best to see that the legal system does not become a scapegoat in the eyes of the public for what I fear may be perceived as the unjust and inhumane denial of any significant measure of compensation to the plaintiffs. ‘The law must take its course’ is not an attractive principle in the context of this case.”*<sup>132</sup>

The statement by the judge was made on 26 June 1990. Both sides responded in their own way.

## Department of Health reaction to the letter from Justice Ognall

So far as government was concerned, the Chief Medical Officer (“CMO”) sent a minute to the Minister of State for Health and to Kenneth Clarke as Secretary of State on 20 July throwing his weight behind the judge’s recommendation and suggesting some payments should be made.<sup>133</sup> Whereas he might be seen as supporting compromise, an opposite view was taken by senior civil servants. On 24 July 1990 Strachan Heppell, a senior civil servant, sent advice to the CMO, the Minister of State for Health and the Secretary of State, covering a submission from Charles Dobson.<sup>134</sup> Following advice from counsel, and a submission from regional directors of public health,<sup>135</sup> Strachan Heppell said that the choices boiled down to

131 Letter from Sir Harry Ognall 26 June 1990 p1 DHSC0046964\_024

132 Letter from Sir Harry Ognall 26 June 1990 pp2-3 DHSC0046964\_024

133 Memo from Donald Acheson to Virginia Bottomley and Kenneth Clarke 20 July 1990 HSOC0017025\_004. Virginia Bottomley was Minister of State for Health between October 1989 and April 1992.

134 Memo from Strachan Heppell to CMO, Minister of State for Health and Secretary of State 24 July 1990 DHSC0046962\_183, Note to Ministers on Haemophiliacs: AIDS Litigation July 1990 DHSC0004360\_147. Charles Dobson reported through an Under-Secretary to Strachan Heppell who was the Deputy Secretary. Written Statement of John Canavan para 1.9 WITN7115001. Although litigation was taking place in Scotland, there is no reference here to there having been any cross border consultation.

135 Submission from Regional Directors of Public Health on HIV Litigation 29 June 1990 DHSC0046964\_006. They agreed that the defence was sound, apart from a possible handful of cases, but that people with haemophilia represented a particular group which deserved a generous settlement and that “*thrashing out these issues in Court will not be in the best interests of patients or the NHS.*”

two: continuing to resist the present action firmly whilst being ready to consider further help through the Macfarlane Trust; or, secondly, seeking a settlement out of court in one form or another. He recommended that government should not follow *“the route mapped out by Mr Justice Ognall.”* He concluded by saying: *“At the same time, in recognition of the very special circumstances of the haemophiliac families, further payments under the MacFarlane Trust would be very welcome and help to make the Government’s position look less hard-nosed and unyielding.”*<sup>136</sup>

Kenneth Clarke maintained his view that the Government was likely to win and, although he said in evidence to the Inquiry that he did not fundamentally disagree with much of what the judge had said, did not think it persuaded him that there should be a settlement. He said the judge was *“setting out the same principles that had led us to give the money to the Macfarlane Trust.”*<sup>137</sup> His Private Office responded to Strachan Heppell on 31 July: he was *“in favour of sticking to our legal defence and continuing to fight the action. He does not think it is necessary at this stage to send a minute to the Prime Minister and he considers that the decision should be communicated to the Judge and the Plaintiffs’ solicitors in strict confidence.”*<sup>138</sup> As he said in evidence, everyone had concluded that an ex gratia payment was the best way of handling the matter: there was *“a case for using public funds to make some compensation”*.<sup>139</sup>

Nonetheless he sought to discuss the issues of settlement with the Chief Secretary to the Treasury, in late September 1990. In Treasury advice under a paragraph headed *“Mr Clarke’s dilemma”* it was said of his views that: *“Mr Clarke is instinctively disinclined to proceed [with an out-of-court settlement] while being aware that the Government is likely to encounter severe criticism whatever it does. He has not, however, made up his mind and would like to discuss the position with you, especially given the large potential financial implications.”*<sup>140</sup>

What was for discussion were three main options as the Department of Health then saw them: to indicate a willingness to negotiate an out-of-court settlement, to decline negotiation and let the court case take its course, or to make a payment into court. The Treasury advice suggested taking the second option, which Kenneth Clarke instinctively favoured.<sup>141</sup>

By late October the position had not changed: Kenneth Clarke, with the support of the then Chief Secretary to the Treasury Norman Lamont, did not approve of the idea that the central defendants should settle the litigation, though they thought that once the case had run its course and the expected judgment in favour of the Government had resulted, they would then make a substantial payment to the Macfarlane Trust.<sup>142</sup>

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136 Memo from Strachan Heppell to CMO, Minister of State for Health and Secretary of State 24 July 1990 p2 DHSC0046962\_183

137 Lord Kenneth Clarke Transcript 28 July 2021 p211 INQY1000142

138 Memo from Helen Shirley-Quirk to Strachan Heppell 31 July 1990 DHSC0046964\_007

139 Lord Kenneth Clarke Transcript 28 July 2021 p221 INQY1000142

140 Memo from Andrew Edwards to Chief Secretary 28 September 1990 p3 HMTR0000001\_039

141 Memo from Andrew Edwards to Chief Secretary 28 September 1990 p6, p3 HMTR0000001\_039

142 Memo from Stephen Bowden to Andrew Edwards 23 October 1990 HMTR0000002\_002, Lord Kenneth Clarke Transcript 29 July 2021 pp28-30 INQY1000143

## Plaintiffs' reaction to the letter from Justice Ognall

The response of the plaintiffs to the judge's views took a different course. On 7 September 1990, the plaintiffs' lawyers wrote to the central defendants in response to Mr Justice Ognall's observations and proposed that consideration be given to a settlement.<sup>143</sup>

What then happened is indicated by a Department of Health summary of the campaign for the settlement.<sup>144</sup> From that it appears that though the lead firm of solicitors, Pannone Napier, had suggested a settlement figure of £80-90 million plus costs in informal discussions with the solicitors for the health authorities, they had indicated that a settlement might be reached at a lower figure. Though Kenneth Clarke did not wish to initiate any negotiations, nonetheless with the Department of Health's knowledge the health authorities (who were also defendants to the action) encouraged Pannone Napier to explore with the other solicitors for the plaintiffs whether they could agree a realistic settlement figure which could be offered to the Department of Health.<sup>145</sup>

In response, the plaintiffs made written proposals for a settlement in the range of £30-60 million. They invited the Department of Health to make an offer in the upper end of the range. Kenneth Clarke met counsel on 1 November to discuss it. He confirmed that there should be no offer from the Department of Health, but counsel would make known to the plaintiffs that if they were to suggest a settlement figure around £20-25 million it might be considered: it would have to be acceptable to all plaintiffs and end the litigation. The advice of counsel to the Department of Health suggested that though the Government defendants should be able to defeat the claims there were "*a number of areas of risk and therefore it would be unwise to proceed on the assumption that all the plaintiffs' claims will certainly fail.*"<sup>146</sup>

Since Mr Justice Ognall's letter, and the plaintiffs' letter of 7 September proposing that settlement be considered, the Court of Appeal hearing had taken place.

That is how the position stood at the beginning of November 1990.

## Reaching the settlement

At the very start of November 1990 there was political change. Geoffrey Howe resigned from Margaret Thatcher's Government on 1 November. This prompted a reshuffle. That led to Kenneth Clarke leaving the Department of Health and William Waldegrave becoming the Secretary of State on 2 November, a Friday. The following Monday counsel for the central

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143 Letter from Pannone Napier to Treasury Solicitor 7 September 1990 DHSC0020866\_134

144 Provided as briefing to the next Secretary of State on 6 November 1990. Memo from John Canavan to Charles Dobson and Stephen Alcock 6 November 1990 DHSC0004365\_008, Present Position on HIV/ Haemophilia Litigation 5 November 1990 DHSC0046962\_187

145 Present Position on HIV/Haemophilia Litigation p2 DHSC0046962\_187

146 Present Position on HIV/Haemophilia Litigation pp2-3 DHSC0046962\_187



defendants met lead counsel for the plaintiffs. The government lawyers indicated that they could not initiate a compromise but were prepared to listen.<sup>147</sup>

The steering committee of the plaintiffs met that evening, and a further meeting between counsel for the parties was arranged for the Wednesday evening.<sup>148</sup> On Friday 9 November 1990 the plaintiffs' lawyers proposed settlement. The proposed heads of compromise began by saying "*The Plaintiffs' counsel would be prepared to advise the Steering Committee and individual Plaintiffs to settle their cases for payments of categorised amounts to the MacFarlane (Special Payments) Trust totalling approximately £42M [million]*" subject to instructions from the clients.<sup>149</sup> The figures were to cover all the people with haemophilia registered with the Macfarlane Trusts as well as all the plaintiffs, and did not include any previous payments made to the Macfarlane Trusts. It then set out a table showing different figures for different categories of plaintiffs, including people who were concerned that they may become infected with HIV because of their association with someone infected.<sup>150</sup> Different figures were given for each category. A further condition was that state benefits would not be affected by the payments, and that medical negligence cases brought against the health authorities rather than the central defendants would be allowed to continue if they fell within certain criteria.<sup>151</sup>

As far as William Waldegrave was concerned there was a shift when John Major became Prime Minister at the end of November. Lord Waldegrave told the Inquiry that there was a moral responsibility for the Government: that it would have been a horrible experience for those making the case to have to go to court, and damaging for the Government because of the bad press they would take for being heartless. The moral case was, in his view, justified since it was not all down to the actions of a single clinician who had been negligent but to wider matters.<sup>152</sup> He was advised by the Department of Health and by the Treasury that the figure was "*on the high side*", and "*We're going to have great trouble getting the money from the Treasury.*"<sup>153</sup> He observed:

*"on the other hand there is the anxiety that we would have what I think is referred to in the papers as a public auction from the other side. And I believed that this*

147 Note by Ronald Powell of telephone conversation with Justin Fenwick 7 November 1990 p1 DHSC0004365\_043

148 Note by Ronald Powell of telephone conversation with Justin Fenwick 7 November 1990 p1 DHSC0004365\_043, HIV Haemophiliac Litigation: Proposed Heads of Compromise November 1990 p1 DHSC0003654\_117

149 HIV Haemophiliac Litigation: Proposed Heads of Compromise p1 DHSC0003654\_117. It went on to explain: "*The proposal is made on the instructions of the Plaintiffs' Steering Group of solicitors but without the knowledge of the lay clients and their individual solicitors; accordingly it is subject to Counsel advising their clients and taking appropriate instructions from lay clients.*"

150 The Department of Health understood this proposed category to include sexual partners, parents, siblings and others. Memo from John Canavan to Charles Dobson and Stephen Alcock 12 November 1990 p2 DHSC0046962\_028

151 HIV Haemophiliac Litigation: Proposed Heads of Compromise DHSC0003654\_117. See, generally, for a description of what happened in slightly greater detail the evidence of Justin Fenwick KC. Justin Fenwick KC Transcript 9 June 2022 pp118-136 INQY1000213

152 Lord William Waldegrave Transcript 5 July 2022 pp35-36, pp55-56, pp69-71 INQY1000220

153 Lord William Waldegrave Transcript 5 July 2022 p64 INQY1000220

*was one of those moments in – – that sometimes happen in any negotiation where there was a chance of agreement and that if you went for it quickly, it could be agreed. And if there was a long process of discussion, whether public or private, it was very likely to come to pieces and we'd be back where we were in the first place, which I thought was a horrible position both for the victims and for the Government. That's why I was so anxious for speed. And I notice that in the notes from Rupert Jackson he talks about the need for speed.”<sup>154</sup>*

He considered that there were two arguments which were key to winning the argument with the Treasury. *“The victims’ lawyers have come forward with an offer that they say will be seen as fair by their clients. This will not recur, we’ve got to do this and do it quickly. And look at the numbers; you can afford them, we can afford them. We both knew the issues surrounding the people. This was why it had to be done now and quickly. And it was affordable.”<sup>155</sup>*

He went through the issues in detail with the new Chief Secretary to the Treasury, David Mellor, on 6 December 1990 and an approach was agreed by the two departments. On 7 December William Waldegrave wrote to the Prime Minister, concluding that the cost of a settlement as proposed by counsel for the plaintiffs would be higher than the most favourable outcome from fighting and winning the case, but much lower than the cost of fighting and losing the case badly, and recorded that the leading counsel for the plaintiffs had told Andrew Collins QC (who acted for the Government) that the settlement would stick and that he would advise the steering committee to accept it, but that the longer matters dragged on the more difficult it would be for him to get agreement from his clients.<sup>156</sup> The minute to the Prime Minister continued:

*“The Chief Secretary and I believe that we should not pass by a possible opportunity to settle this very difficult issue. We are coming under increasing pressure to settle, not least from our own backbenchers. Settlement now would enable us to avoid the long-drawn-out court cases, beginning next March, in which public sympathy will be with the haemophiliacs. It will also strengthen our position in dealing with Rosie Barnes’ Private Members Bill on no-fault compensation. The amounts payable per person ... would not be publicly regarded as overly generous ... We think it would be better to settle on the figures proposed by the haemophiliacs’ counsel ... than to bargain publicly for lower figures, which would carry the risk of sparking a public auction in which the Government would receive little credit and could end up by paying more.”<sup>157</sup>*

Amongst further matters to which the Ministers gave particular importance were that *“recipients of the new money would have to undertake to drop the existing cases and*

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154 Lord William Waldegrave Transcript 5 July 2022 pp64 INQY1000220

155 Lord William Waldegrave Transcript 5 July 2022 pp73-74 INQY1000220

156 Memo from William Waldegrave to Prime Minister 7 December 1990 p2 HMTR0000002\_019

157 Memo from William Waldegrave to Prime Minister 7 December 1990 p3 HMTR0000002\_019

*forswear bringing any future cases on the matter*”, all the plaintiffs would need to accept the settlement, the medical negligence cases would have to be identified for settlement out of court in accordance with agreed criteria, and the terms of acceptance should be carefully considered with legal advisers so as to “*minimise difficult precedents for the future.*”<sup>158</sup>

John Major, who formally became Prime Minister on 28 November 1990, commented in evidence to the Inquiry: “*It would have been absurdly foolish ... not to have taken the opportunity of settling an issue that had caused a great deal of anguish for the victims. But also was dragging on for so long that one needed a definitive settlement. And it seemed to me that it was entirely right, and if that could be an agreed settlement, rather than imposed settlement, it was far more likely to be acceptable.*”<sup>159</sup>

The submission from William Waldegrave had gone in his weekend box. His civil servants told him that there were significant risks, but that the Health Secretary, Chief Secretary to the Treasury, Social Security Secretary, and counsel all thought that those were outweighed by the advantages.<sup>160</sup>

## Announcement of settlement

On the Monday, 10 December, the Prime Minister agreed to the proposals.<sup>161</sup> William Waldegrave then wished to make the announcement on the very next day that there was an agreement in principle to accept the deal that the plaintiffs’ counsel had put forward.<sup>162</sup> Despite intra-departmental concern about this, because it would come in advance even of a reaction from the steering committee of solicitors representing the plaintiffs, William Waldegrave secured an agreement to his proposal.<sup>163</sup>

When asked in evidence why he wanted to announce it whether or not there had been any agreement with the plaintiffs’ representatives, and in circumstances where the plaintiffs themselves clearly would not all have agreed, he said:

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158 Memo from William Waldegrave to Prime Minister 7 December 1990 p4 HMTR0000002\_019

159 Sir John Major Transcript 27 June 2022 p97-98 INQY1000219

160 Memo from Dominic Morris to Prime Minister 7 December 1990 p2 CABO0000044\_007

161 Memo from Dominic Morris to Stephen Alcock 10 December 1990 HMTR0000002\_020

162 This led to some tension with the Treasury. Jeremy Heywood (Private Secretary to the Chief Secretary to the Treasury) wrote: “*Crucially, Mr Waldegrave apparently wishes to make this announcement whether or not the steering committee of lawyers representing the Haemophiliacs has signalled its agreement to Counsel’s proposals ... This is of course completely at odds with what the Chief Secretary agreed with Mr Waldegrave last week, and inconsistent too with the Prime Minister’s view ... Having discussed this with the Chief Secretary, I have suggested to No. 10 and to the Department of Health an alternative form of words, against the contingency that the steering committee does not agree with the plaintiffs’ Counsel’s proposal this afternoon.*” [The alternative form of words was essentially just referring to ongoing discussions.] Jeremy Heywood continued: “*No 10 thought this was exactly right; the Department of Health did not. Mr Waldegrave phoned the Chief Secretary on the carphone to make clear his view that a public announcement that the Government was prepared to deal would in fact help to secure the steering committee’s agreement. The Chief Secretary expressed the contrary view and said that it was not in Mr Waldegrave’s own interests to do anything that would increase the risk of the Government being driven to accept a more generous settlement. The Treasury had already been more than generous.*” Memo from Jeremy Heywood to Norman Lamont 11 December 1990 HMTR0000002\_021. Emphasis in the original.

163 Memo from Jeremy Heywood to Norman Lamont 11 December 1990 p1 HMTR0000002\_021

*“Well, two things. As is said in that minute, I’m not going to get any more money. That’s the threat from the Chief Secretary saying it’s in my interest to do what he thinks is best, because I won’t get any more money. Second, looking that weekend, I think, or that Monday – – and I can’t remember – – at the tactics that I’d agreed with the Treasury, they are very foolish tactics. The idea that more than a thousand people could agree and only at that point, when they’d all agreed, would we say that we were going to accept the offer from their side, would be bound to result in a public auction. And as I’m being warned by the Treasury, I won’t get any more money for that. So there was a real risk that the whole deal was going to come to pieces at that point and we’d be back where we were. So that, concentrating on it – – I don’t know what else I was doing that weekend or where I was – – concentrating on it, it seemed to me that what I’d agreed and what the Treasury thought was a good thing to do was bound to fail, and therefore I’d put to the Prime Minister clearly that we should do it in the other way, which then worked. And I’m glad that I did that, because having a momentary froideur with the Treasury was well worth getting what I thought and what Mr Rupert Jackson thought and Mr Andrew Collins thought was a fair deal through and done. And it worked.”*<sup>164</sup>

Accordingly, although the steering committee had not yet accepted the proposals which counsel had said they would recommend to the committee, nor had individual plaintiffs presumably told the steering committee of their approval,<sup>165</sup> the Prime Minister announced the settlement orally to Parliament on 11 December 1990. He did however indicate when doing so that the settlement still had to be formally approved by individual plaintiffs and in the case of minors by the courts.<sup>166</sup> The Haemophilia Society did not itself represent

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164 Lord William Waldegrave Transcript 5 June 2022 pp95-97 INQY1000220

165 These are matters which cannot be explored further here because they are covered by legal professional privilege between the plaintiffs and their legal advisers. As to Scottish litigation, which was under the terms of the Parliamentary announcement effectively covered by it, the steering committee did not include any of the Scottish lawyers. The solicitor who was chairman of the Scottish Haemophilia/HIV Litigation Group wrote to the Secretary of State for Scotland, Ian Lang, on 12 December: *“Not only were the Scottish lawyers excluded from the discussions with the Government, they were not even advised that these discussions were taking place.”* Letter from Alfred Tyler to Ian Lang 12 December 1990 p1 PRSE0003064

166 He answered a question as to when he expected to be *“in a position to act on this deep human tragedy”* by saying: *“I can now tell the House that the Government has been examining this matter and have been able to agree in principle to proposals put forward by the plaintiffs’ lawyers. Provided that the proposals are formally approved by individual plaintiffs – and in the case of minors, by the court – they should provide a basis for bringing the matter to an agreement successfully and soon. My right hon. Friend the Secretary of State for Health will inform the House of the details.”* Hansard Extract Oral Answer 11 December 1990 DHSC0003654\_003. William Waldegrave then provided a written answer which read in its material parts as follows: *“The steering committee of solicitors representing the HIV haemophiliac plaintiffs and their counsel have put forward to the Department of Health proposals for the settlement of this litigation which they regard as a fair and reasonable resolution of the plaintiffs’ claims. The Government have carefully considered these proposals and agree that they will provide a fair and proper way of ending this litigation and of making financial provision for all affected haemophiliacs and their dependants, whether or not they have joined in the litigation. We believe that our case is legally strong and that the plaintiffs would not succeed in proving negligence on the part of the Department of Health. None the less the Government have always recognised the very special and tragic circumstances of the haemophiliacs infected by HIV and of their families. We recognise too the harrowing effect legal action would have on them. The Government have therefore*

any of the plaintiffs, though many were members of it, and it had campaigned vigorously for compensation. In a press release the Society described its reaction as one of “grave disappointment”. The general secretary, David Watters, both praised the two politicians at the centre of the Government’s reaction – he described it as “a triumph for a caring Prime Minister and Secretary of State for Health. John Major and William Waldegrave are to be applauded for addressing this problem so promptly” – and said “it is unfortunate the settlement has been so low.”<sup>167</sup> David Watters wrote to local group officers and the executive committee the next day:

*“It came as more than a surprise on Tuesday afternoon to learn that the lawyers involved in the HIV litigation had agreed on a package to recommend to individual plaintiffs. It came as more of a surprise that the announcement was made in the House of Commons without the proposal having been put to those taking legal action themselves!”*<sup>168</sup>

The following month David Watters wrote to William Waldegrave: “While the vast majority of our members have indicated their intention to accept, this is being done with resignation and disquiet, recognising that there is really no option since it is financially impossible to fight on.”<sup>169</sup>

With regards to the cases in Scotland and Northern Ireland, Strachan Heppell advised William Waldegrave on 14 December 1990:

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*agreed in principle to meet the steering committee’s proposals. In outline, the compromise would result in the Government providing to the Macfarlane Trust, in addition to the £34 million already paid, a further sum of about £42 million, for distribution to all haemophiliacs and their families according to their respective circumstances. Furthermore, the Government have agreed that payments from the Macfarlane Trust will not affect entitlement to social security and other statutory benefits. The plaintiffs’ reasonable legal costs would also be paid by the Government. Because the proposed settlement will require the formal approval of all individual plaintiffs, and in the case of minors, of the court, it would be inappropriate at this time to publish further details, until all plaintiffs and the court have had an opportunity to consider the full terms of the settlement and to approve them. The Government would apply the outcome of any settlement to all parts of the United Kingdom. The Government welcome these developments, which offer a speedy way of ending the lengthy period of uncertainty for haemophiliacs and their families and of giving them additional financial security.”* Hansard Extract Written Answer 11 December 1990 p2 DHSC0004415\_036

167 Haemophilia Society Press Release *Settlement Announced for those with Haemophilia and HIV* 11 December 1990 p1 HSOC0019519

168 Haemophilia Society Press Release *Settlement Announced for those with Haemophilia and HIV* 11 December 1990 p4 HSOC0019519

169 Letter from David Watters to William Waldegrave 22 January 1991 DHSC0003657\_011

*“We have been working on the basis that as before the matter will be settled on a UK basis. If the Scots decided not to settle on the same basis as the English and Welsh litigants we might have a handling problem. But we doubt whether this will happen. We would not release any of the money to Scotland or Northern Ireland until the litigants had signed up to the same arrangements as in England and Wales. If the Scots did not do so, the offer would be taken off the table for Scotland and the Scots litigants would run the risk of not getting anything.”<sup>170</sup>*

## The pressure to settle

It is plain from the evidence which the Inquiry has received that many of those involved as plaintiffs in the litigation felt that they had no real choice but to accept the settlement. The wife of one of the plaintiffs explains that:

*“The Government then announced a settlement payment in December 1990 and [my husband] attended a meeting in London with Mark Mildred of Pannone Napier to discuss the matter. HIV infected haemophiliacs and all litigants, or at least a commanding majority, had to accept the offer, drop the litigation, and sign a waiver of rights ... The legal action involved a difficult and voluminous case and [my husband’s] decision, based on the premise the Government would never do the right thing in a unique and tragic medical case nor admit liability for criminal negligence, was to take the offer which was £60,500 for him. This settlement was distributed early summer 1991. Plaintiffs were dying every month and [my husband] was worried about my future. This is the only time I ever heard [my husband] swear and he was furious knowing that despite all his efforts for his family we were going to lose him, with the knowledge he would die a terrible death. His opinion was that this offer was shameful and nothing for a person’s life let alone his earnings potential and the loss of our family life together.”<sup>171</sup>*

Her husband died in 1995.

Joan Pugsley’s husband Philip was also a plaintiff. A local newspaper article on 20 December 1990 highlighted the dilemma for Philip and the other plaintiffs:

*“They can either accept the relatively small share offered to them or face a long court battle that they may not live to see resolved ... The Pugsleys have been advised by their solicitor to accept the offer even though it is smaller than they might have expected, since to fight for a larger payment could involve a protracted court battle lasting as long as five years, with no guarantee of a satisfactory outcome at the end of it. By that time, in any case, many of the sufferers will be dead.”*

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170 Memo from Strachan Heppell to Stephen Alcock 14 December 1990 DHSC0003664\_173

171 Written Statement of ANON paras 93-94 WITN3204001

A week after the publication of that article Philip was admitted to the Churchill Hospital “for the last time.” He died in early 1991.<sup>172</sup>

Alan Burgess wished that they had had “our day in court ... We might not be here now, because I think the facts would’ve come out and we’d have been in a better place ... I must admit, at the time, prognosis wasn’t that good, and you think, well, they offer you this money, you have to – – you have to accept or nobody gets it.”<sup>173</sup>

Heather Evans, whose husband Perry was a party to the litigation, recalled that “It was Hobson’s choice. It felt like blackmail ... Everybody felt the same”.<sup>174</sup> A woman whose son was infected with HIV did “not think that the settlement reflected what we had suffered, particularly if things were going to get worse. We did not seem to have a choice though, so we accepted the money.”<sup>175</sup> One woman explained that her husband was in hospital when the proposed payments were announced on the news: “He was devastated by the derisory figures. On hearing that statement [he] gave up and sadly passed away before he was able to receive the cheque.”<sup>176</sup> Alice Mackie describes a similar pressure in Scotland to accept the settlement offer.<sup>177</sup>

## The waiver

When David Mellor and William Waldegrave presented their agreed position to the Prime Minister over the weekend of 7-10 December 1990 a point to which they attached particular importance was that “recipients of the new money would have to undertake to drop the existing cases and forswear bringing any future cases on the matter”.<sup>178</sup> That foreshadowed what has become known as “the waiver”.

Dr Rejman sent a memo to the solicitor acting for the Department of Health in the litigation, Ronald Powell, on 22 February 1991 about individuals who were HIV negative and as such not covered by the HIV haemophilia general settlement, bringing litigation about hepatitis infections. He said: “I believe that any that are HIV positive would have to agree not to raise hepatitis in any further litigation, but this obviously does not exclude those not in the scheme.”<sup>179</sup>

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172 Written Statement of Joan Pugsley para 116, paras 63-68 WITN4603001

173 Alan Burgess Transcript 28 October 2019 pp62-64 INQY1000045. He added, in relation to the waiver, that it “was sort of like moral blackmail, really”. He was unaware that he had been infected with Hepatitis C until April 1995.

174 Written Statement of Heather Evans para 33 WITN2718001

175 Written Statement of ANON para 53 WITN0040001

176 Written Statement of ANON para 59 WITN1470001

177 Written Statement of Alice Mackie para 42 WITN2189001

178 Memo from William Waldegrave to Prime Minister 7 December 1990 p3 HMTR0000002\_019. Another point was “all the plaintiffs would need to accept the settlement (though we may have in practice to relax this a little). The medical negligence cases would have to be identified for settlement out of court in accordance with agreed criteria.”

179 Memo from Dr Rejman to Ronald Powell 22 February 1991 DHSC0004766\_068

When it was put to him during his evidence to the Inquiry that his minute might have been the genesis of what later became a general undertaking not to sue in respect of hepatitis he did not agree that the idea came from him. By using the words “*I believe*” he said he was not expressing a new idea but recognising an established position, that he had been given to understand from earlier exchanges amongst those working in and for the Department of Health.<sup>180</sup>

It follows from the fact that reference was made to forswearing further claims in the conversation between the Chief Secretary and the Secretary of State that the idea of surrendering rights to make further claims was not a new one: but it remains the fact this was the first reference to hepatitis of which there is any documentary record. Although a more natural reading of the words beginning with “*I believe that*” would be that they were making a suggestion to others, the words also fit what Dr Rejman is describing. As matters proceeded, the question of whether there should be a waiver or not, and the terms of it, were matters for open discussion and agreement between the plaintiffs’ and the defendants’ respective legal teams – what is recorded below evidences this.

It was common in personal injury litigation at least during the 1990s and early 2000s that where a claim was settled there should be an acceptance by the plaintiffs that they would not re-litigate in respect of any other illnesses arising out of the same set of facts. Strictly speaking, such an undertaking is unnecessary as a matter of law, since it is a general legal principle that a person should bring forward all the claims that arise out of a given set of facts in one and the same action. This is known as the rule against multiplicity of actions. However, it is also recognised that this rule should not create an injustice, so that, potentially, if in all the circumstances justice requires it, a further action can still be brought. An agreement made between two competent adults may however be enforceable even if there is an argument later that it is unfair: in effect, the agreement precludes the chances of this argument succeeding.

In respect of the litigation, therefore, the lawyers acting for both parties would not be surprised to see a term included in the final agreement which precluded any further action arising out of the same set of facts. The agreement to be reached on settlement reflected this in its various drafts, before reaching a final form.

The earliest consideration of what, if any, restrictions to place upon the plaintiffs as a condition of receipt of payment under the settlement agreement came on 12 December – the day after the announcement had been made to Parliament, and well before Dr Rejman’s reference to what he believed to be the case. A draft read: “*The Plaintiffs will discontinue their actions against all Defendants and will undertake not to bring fresh proceedings, save that those Plaintiffs who have already made allegations as to clinical management shall be*

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180 Andrzej Rejman Transcript 11 May 2022 pp1-5, p21 INQY1000204. I am inclined to accept Dr Rejman’s evidence on this, and that the origins of the idea of a waiver lay elsewhere.



*entitled to pursue that element only of these claims against the relevant Health Authority.*” (It went on to define the “medical negligence” cases more closely.)<sup>181</sup>

This was then expanded in a further draft of 21 January 1991. The relevant parts read: *“The Plaintiffs will discontinue their actions against all Defendants and will undertake not to bring fresh proceedings against any Defendant or against any other Government Department, health authority or treating doctor”*. There was the same exception for medical negligence cases already brought.<sup>182</sup>

Neither of these two iterations define the nature of the claims to which the words “*fresh proceedings*” related. However, the wording now went beyond those who had been named as defendants in the original action. It covered treating doctors.

On 23 March 1991 the draft was refined further. This time the fresh proceedings were more closely identified:

*“The Plaintiffs will discontinue their actions against all Defendants and will undertake not to bring fresh proceedings against any Defendant or against any other Government Department, Health Authority or treating doctor in respect of the administering of cryoprecipitate, Factor VIII or Factor IX, save for those Plaintiffs whose code numbers are set out in Schedule Seven hereto shall be entitled to pursue that element only of these claims against the relevant Health Authority”*.<sup>183</sup>

The latter words refer to ongoing medical negligence claims.

This was followed by correspondence on 16 April 1991. This showed the amendments which the plaintiffs’ lawyers wished to make to the suggested text. These included adding the words: *“Nothing herein shall prevent a Plaintiff from bringing proceedings in respect of the administering prior to 13th December 1990 of cryoprecipitate, Factor VIII or Factor IX where (i) that has caused damage ... which had not been diagnosed by 13th December 1990; and/or (ii) the damage alleged does not include infection or risk of infection by HIV and/or the hepatitis viruses.”*<sup>184</sup> By 22 April 1991 these suggestions had been incorporated into the then current draft. It read:

*“The Plaintiffs will discontinue their actions against all Defendants and will undertake not to bring fresh proceedings against any Defendant or against any other Government Department, Health Authority or treating doctor in respect of the administering prior to 13th December 1990 of cryoprecipitate, Factor VIII or Factor IX, save that: – (1) those Plaintiffs whose code numbers are set out in Part 1 of Schedule Eight hereto shall be entitled to pursue that element only of these*

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181 HIV Haemophilia Litigation Draft Proposed Detailed Terms of Settlement 12 December 1990 p1, p9 DHSC0003654\_032

182 HIV Haemophilia Litigation Draft Proposed Detailed Terms of Settlement 21 January 1991 p11 DHSC0004523\_091

183 HIV Haemophilia Litigation Draft Proposed Detailed Terms of Settlement 22 March 1991 p12 DHSC0003660\_019

184 HIV Haemophiliac Litigation Draft Settlement Agreement 16 April 1991 p1 DHSC0003661\_022

*claims which relates to the allegations of medical negligence against the relevant Health Authorities ... and (2) nothing herein shall prevent the Plaintiff from bringing proceedings in respect of the administering prior to the 13th December 1990 of cryoprecipitate, Factor VIII or Factor IX, where: – (i) that has caused damage to such Plaintiff which had not been diagnosed prior to the 13th December 1990; and/or (ii) the damage alleged does not include infection or the risk of infection by HIV and/or the hepatitis viruses.”*<sup>185</sup>

This therefore, if agreed, represented an agreement not to make a claim about infection with HIV or hepatitis as a result of treatment administered before 13 December 1990.

It therefore appears that this amendment in these particular terms was first proposed by the plaintiffs' lawyers.

As pointed out, a clause restricting further proceedings would not be unexpected in settlements relating to personal injury claims at the time. Some five days later, Ronald Powell produced a final draft (it was dated 26 April 1991, but sent to the plaintiffs on 1 May 1991). It read in the relevant parts:

*“The Plaintiffs will discontinue their actions against all Defendants and will undertake not to bring fresh proceedings against any Defendant or against any other Government Department, Health Authority or treating doctor in respect of the administering prior to 13th December 1990 of cryoprecipitate, Factor VIII or Factor IX, save that: – ... nothing herein shall prevent a Plaintiff from bringing proceedings in respect of the administering prior to 13th December 1990 of cryoprecipitate, Factor VIII or Factor IX where the damage alleged does not include infection or the risk of infection by HIV and/or the hepatitis viruses.”*<sup>186</sup>

That represented the final version of the document so far as people in England and Wales were concerned. Anyone who wished to take advantage of the settlement sums, and anyone who had not been a plaintiff, but was in the same situation – that is, they had been infected with HIV by treatment with blood or blood products prior to 13 December 1990 – would have to sign a document which contained an undertaking not to bring proceedings about infection with HIV or hepatitis.

The terms of the waiver undertaking which was to be signed by each individual were, however, not identical to the terms which had finally been put as the terms of settlement to which the plaintiffs' lawyers agreed on behalf of the plaintiffs. The waiver in its material parts read as follows:

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185 HIV Haemophilia Litigation Draft Main Settlement Agreement 22 April 1991 pp15-16 SCGV0000233\_040

186 HIV Haemophilia Litigation Main Settlement Agreement 26 April 1991 pp20-21 HSOC0023174. Charles Dobson had briefed the Secretary of State on 19 April 1991 that: *“Once the final form of the England and Wales settlement is available, colleagues in Scotland and Northern Ireland will be able to make a similar offer to end the separate litigation in those two countries.”* Memo from Charles Dobson to Stephen Alcock 19 April 1991 p2 DHSC0003662\_090

*“In expectation of receiving from the Macfarlane (Special Payments) (No.2) Trust the sum of £23,500 I undertake with the Secretary of State for Health that I will not at any time hereafter bring any proceedings against the Department of Health, the Welsh Office, the Licensing Authority under the Medicines Act 1968, the Committee on Safety of Medicines, any district or regional health authority or any other Government body involving any allegations concerning the spread of the human immuno-deficiency virus or hepatitis viruses through Factor VIII or Factor IX whether cryoprecipitate or concentrate) administered before 13th December 1990.”*<sup>187</sup>

The words “concerning the spread of the human immuno-deficiency virus or hepatitis viruses through Factor VIII or Factor IX whether cryoprecipitate or concentrate) administered before 13th December 1990” replaced “in respect of the administering prior to 13th December 1990 of cryoprecipitate, Factor VIII or Factor IX”. The reason for this change of wording is opaque, though could possibly have some relation to secondary transmission from a person directly infected by the treatment they had received. However, the precise interpretation of this, in its context, has never been subject to the decision of any court.

Just as many plaintiffs felt that they had no choice but to accept the settlement offer, they felt that they had no choice but to sign the waiver. A widow recalls that her husband “*didn’t want to sign it but he didn’t think he could afford to fight on alone, either practically or financially. In the end he gave in.*”<sup>188</sup> Denise and Colin Turton, whose son Lee was infected with HIV, describes how “*Lee was ill at the time. It was ’91, he wasn’t very well and we’d been asked to sign the form to say that we would not take anything further and we refused, we kept refusing and then we had the solicitor kept asking, saying, ‘If you don’t sign – – you need to sign because if you don’t do it nobody else will get anything’, and in the end we only had three days in which to sign it because we kept saying no, so we signed it because we were told that if we didn’t nobody would get anything and then they told us afterwards that Lee’s money, even though he was dying, would be put in trust until he was 18.*”<sup>189</sup> Lee did not live to see 18. He died in January 1992, aged ten.

### **The waiver in Scotland**<sup>190</sup>

Following the announcement in December 1990, settlement negotiations in Scotland proceeded separately from those taking place in relation to England and Wales, although Scottish Office officials proposed to rely “*where possible on the wording of the English*

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187 Terms of Macfarlane Special Payments Trust Waiver Undertaking 1991 MACF0000086\_225

188 Written Statement of ANON para 83 WITN1303001

189 Denise and Colin Turton Transcript 8 October 2019 p30 INQY1000037

190 See also Appendix to Presentation Note – Undertakings in HIV Haemophilia Litigation and Blood Transfusion Scheme 2023 INQY0000441 and Addendum Note on Scottish Office and Scottish Home and Health Department Decision-Making – Undertakings in HIV Haemophilia Litigation and Blood Transfusion Scheme January 2023 INQY0000442

*settlement*” and not to change the wording unless it was thought necessary<sup>191</sup> and there was ongoing contact and discussion between the Scottish Office and Department of Health lawyers.

Over the following 12 months discussions continued in parallel between the Department of Health solicitor (Ronald Powell), and the solicitor acting in the litigation for the Secretary of State for Scotland (Richard Henderson) on the one hand, and between Richard Henderson and Balfour and Manson, representing the Scottish pursuers, on the other. Thus on 18 April 1991, writing to Balfour and Manson, Richard Henderson suggested draft wording for an undertaking to be provided by the Scottish pursuers and other people with haemophilia who might take advantage of the terms of settlement which did not include a promise not to take any future action in respect of hepatitis.<sup>192</sup> This was in direct contrast with the position in England and Wales. On 26 April a further draft provided by Ronald Powell to Richard Henderson did include an undertaking for Scotland which covered hepatitis as well.<sup>193</sup>

However, following further correspondence and various drafts,<sup>194</sup> the form of undertaking to be included as part of the Scottish terms of settlement was, at first, one which by a draft of 3 May excluded any further action in respect of HIV **and** hepatitis in Scotland as well as south of the border<sup>195</sup> and then, subsequently, changed to omit any reference to limiting future claims for hepatitis.

By 4 June 1991 Richard Henderson wrote to Ronald Powell to say that the Trust Deed and the undertaking not to take further legal action in respect of treatment with factor concentrates or cryoprecipitate in the 3 May form<sup>196</sup> would have to be changed in respect of Scottish pursuers so that it no longer precluded any future action in respect of hepatitis.<sup>197</sup> This became the definitive position. The settlement in Scotland was made on that basis, for it was the formal offer which, through Richard Henderson, the Scottish Office then put to Balfour and Manson for their acceptance on behalf of the pursuers. The Trust Deed (which covered both English and Welsh people with haemophilia and Scots with haemophilia) was accordingly amended to set out, in a schedule, the undertakings to be given by Scottish

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- 191 Memo from Richard Henderson to George Tucker 11 January 1991 p1 SCGV0000231\_037. A draft of settlement terms circulated in the Scottish Office in January 1991 recorded that “*the Government’s intention is that the proposals set out in the English Settlement should with appropriate modification apply in Scotland.*” Draft Proposed Detailed Terms of Settlement of HIV/Haemophilia Claims In Scotland p1 SCGV0000501\_114
- 192 Letter from Richard Henderson to Balfour and Manson 18 April 1991 pp6-7 SCGV0000233\_056
- 193 Letter from Ronald Powell to Richard Henderson 26 April 1991 SCGV0000503\_067, Draft Declaration of Trust Constituting Macfarlane Special Payments Trust 26 April 1991 p25 SCGV0000503\_068. See also the revised version: Memo from Ronald Powell to Richard Henderson 1 May 1991 SCGV0000503\_062, Draft Declaration of Trust Constituting Macfarlane Special Payments Trust 1 May 1991 pp27-28 SCGV0000503\_063
- 194 Addendum Note on Scottish Office and Scottish Home and Health Department Decision-Making – Undertakings in HIV Haemophilia Litigation and Blood Transfusion Scheme paras 41-47 INQY0000442
- 195 Draft Declaration of Trust Constituting Macfarlane Special Payments Trust 3 May 1991 MACF0000083\_004
- 196 Both were necessary since they fulfilled different functions: the Trust Deed provided the mechanism for distribution of the settlement sums; the undertaking/waiver was to prevent claimants both accepting the settlement sums but still suing for more.
- 197 Letter from Richard Henderson to Ronald Powell 4 June 1991 SCGV0000234\_105

litigants.<sup>198</sup> They thus ended up different from those applying in England and Wales because in England and Wales litigants (and non-litigants who as haemophiliacs had been infected by HIV through their treatment) had to undertake not to make or continue any claim in respect of hepatitis as well as HIV, whereas in Scotland they did not.

In 1993 Scottish Home and Health Department officials became aware that the Scottish undertaking was different from the equivalent in England and Wales and sought to understand why. A minute dated 6 October 1993 recorded that: “*A thorough review of our files has revealed no reason why the English scheme includes a clause to ensure no claims can be raised for hepatitis infection following receipt of payment for HIV and the Scottish scheme doesn’t.*”<sup>199</sup>

Though indeed there is no record of the reasons for either version – including hepatitis or excluding it – there were comments in April 1992 which provide some explanation. A minute seeking the approval of the NHS Chief Executive in Scotland recorded that “*strong representations*” had been received from the infected parties through their solicitors that because the settlement had been in respect of HIV, any undertaking to give effect to that settlement should exclude hepatitis infections.<sup>200</sup>

## Commentary

This chapter set out to examine three areas in particular. First, the reaction to the litigation within government which led to a “line to take” being adopted; second, what led to the process of settlement; and third, how it came about that the “waiver” was required: the terms of reference of the Inquiry require it to consider the “*appropriateness of preconditions (including the waiver in the HIV Haemophilia Litigation) imposed on the grant of support from the Trusts and Funds*”.<sup>201</sup>

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198 Letter from Richard Henderson to Balfour and Manson 24 June 1991 DHSC0003635\_065, Detailed Terms of Settlement of HIV/Haemophilia Claims in Scotland pp11-12 BNOR0000329. The Macfarlane (Special Payments) (No.2) deed of trust was varied by deed on 19 September 1991 and the undertaking in the substituted schedule covering Scotland included, as per the agreement made in June 1991 in Scotland, HIV but not hepatitis. Deed of Variation relating to Macfarlane Special Payments Trust 19 September 1991 MACF0000083\_003

199 Memo from Robert Panton to Richard Henderson 6 October 1993 SCGV0000236\_089. When, in 1992, a scheme was being drawn up for patients infected with HIV by blood and tissue transfer in Scotland, the reference to hepatitis in the proposed undertaking was deliberately removed: “*Since the form of undertaking required of applicants under the Haemophiliac Scheme did not refer to hepatitis virus we have not thought it right to insist on an undertaking in respect of hepatitis infection from those who have become infected with HIV as a result of blood transfusion etc.*” Letter from Richard Henderson to Balfour and Manson 10 April 1992 SCGV0000238\_030. See also Memo from George Tucker to Private Secretary of NHS Chief Executive 9 April 1992 p3 SCGV0000239\_024

200 Memo from George Tucker to Private Secretary of NHS Chief Executive 9 April 1992 pp2-3 SCGV0000239\_024. See also Letter from Richard Henderson to J & A Hastie Solicitors 10 April 1992 p2 SCGV0000238\_031

201 Infected Blood Inquiry Terms of Reference para 8(e) INQY0000458

## “Line to take”

As set out towards the start of this section, the Department of Health’s reaction in March 1989 when the first indications of it being sued arose was (quite properly) to seek to establish the facts and to see whether it had dealt properly with those who were suing.<sup>202</sup> There is little to show precisely how it went about that process, but it moved from a state of internal curiosity to one of having a collective strong view that the Government was not itself at all at fault. The submission that first informed the Minister of State about the litigation contained the unevidenced<sup>203</sup> claim that: “*the government has a fair chance of successfully defending its role in the court actions, given that at every stage it has acted as swiftly as possible to minimise the risk of infecting haemophiliacs with AIDS in the light of the best expert opinion available at the time.*”<sup>204</sup> Over time, the government line would become that patients had received the best available treatment in the light of medical knowledge at the time. This conviction would have informed the Department of Health’s instructions to counsel and its own approach to settlement.

Less than two weeks before settlement, a confidential note to the Chief Secretary of the Treasury showed that there were more than 500 sufferers whose infections with HIV “*in principle*” might have been contracted after the stage at which hospitals might reasonably have been expected to use different forms of treatment.<sup>205</sup> In a case with just under 1,000 plaintiffs this, if well founded, was to the effect that just over half the cohort of plaintiffs might have avoided HIV if they had been better treated. The inconsistency between this recognition and asserting a position in which it was said that the best was done at all times does not appear to have struck individuals within the Department of Health, though it is the Department from which the information in this note came. Nor did the trenchant comments of a potential expert such as Professor Rose, thought of by the Department of Health as a possible expert for the litigation, whose views were not consistent with the perceived wisdom in the Department, seem to cause any significant reflection as to whether the Department of Health was right in its collective view.

In short, a view was expressed (not simply internally but to the public) which was both unevidenced and misleadingly confident about the quality of treatment that had been given to people with haemophilia; nor was it retracted from or qualified at all before settlement was reached – and even then for many years thereafter.

## Reaching a settlement

What is clear, however, is that the “line” set out above was taken by all concerned on the defendant side of the litigation. After the observations made in the judgments of the

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202 Memo from John Canavan to Charles Dobson and Graham Hart 16 March 1989 MHRA0017673

203 The oral evidence of the three civil servants, reviewed above, shows that they relied on the opinions of others without knowing what they might be based on. Nor was any evidence offered to the Secretary of State.

204 Memo from Charles Dobson to Alan Davey 26 June 1989 p3 MHRA0017681

205 Memo from Andrew Edwards to PS/Chief Secretary 26 November 1990 p3 HMTR0000002\_009

Court of Appeal on disclosure in September 1990, following on from the observations of Mr Justice Ognall made some six weeks or so beforehand, there began to be some hesitation about whether, from the defendants' perspective, the case remained one which should be fought and not settled. There is no clear evidence that the increasing uncertainty had anything to do with what the Court of Appeal had said, but Government legal advice became less assured than it had been, though it still predicted victory.<sup>206</sup> There then followed the political changes which brought John Major to become Prime Minister and William Waldegrave to be appointed Secretary of State for Health in place of Margaret Thatcher and Kenneth Clarke.

The view expressed to ministers was that the case, though exciting public sympathy, was one which on balance the Department of Health and Government were likely to win. It was brought against more defendants than the "central defendants" whose position has been examined carefully in this section. It was brought, too, against individual doctors and against health authorities. Categories of claims for clinical negligence which could proceed were later set out as an annex to the terms of settlement, presumably in the light of particular allegations made by the plaintiffs in those cases. There was obviously sufficient detail known of the individual claims to enable identification of a number of categories of case which could, depending on the evidence, prove to be well-founded. The settlement provided that these should proceed to trial unless an acceptable settlement were reached in that particular individual case.<sup>207</sup> Apart from such cases (dealt with in the same way as any other claim for damages for clinical negligence would be), however, the Department of Health itself took the lead responsibility for responding to the claims.

There was a mismatch in terms of finance, resources, and in access to knowledge between a Government and a collection of individual plaintiffs represented together as a cohort. Many of the plaintiffs were legally aided. That means that their claims were supported by state funding. Though the Legal Aid Board is independent of government, the risk that it might cease funding the claims if a reasonable settlement<sup>208</sup> were to be refused (especially if only by a handful of plaintiffs) might well have been in the minds of some of the plaintiffs or their lawyers. Some were not entitled to legal aid and were having to make financial contributions towards the costs of the litigation.<sup>209</sup> David Watters said in a letter to William Waldegrave that the majority of the Haemophilia Society's members involved in the litigation were resigned to acceptance of the settlement "*since it is financially impossible to fight*

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206 The timing of the "500 sufferers who might in principle" have avoided infection memo was less than two weeks before settlement was announced. However, there is no evidence that in itself it acted as a catalyst. Memo from Andrew Edwards to PS/Chief Secretary 26 November 1990 pp2-3 HMTR0000002\_009. Doubts about the overconfident "line" were never recorded as such within the Department of Health.

207 The Main Settlement Agreement 26 April 1991 pp32-33 HSOC0023174

208 As it may well have been viewed by the Legal Aid Board, since the overall figure had been proposed by the plaintiffs' counsel, and accepted without any further negotiation, together with a reassurance that payments would not be taken into account for the purpose of social security benefits.

209 See for example Written Statement of Julia Mitchell paras 102-104 WITN1010001, Letters from solicitors and the Haemophilia Society pp4-15 WITN1564044 and Second Written Statement of Mark Mildred para 12.2 WITN5258003

on.”<sup>210</sup> This may well have reflected a concern about continued funding, though it could have reflected a desperation to avoid any delay in getting further funds necessary to avoid the worst of their financial poverty, and may well have reflected both. There is, however, little evidence that the Government intentionally used its power and position to browbeat the plaintiffs into settlement. Nor is there any evidence that the defendants used the likely short lifespan of many of the plaintiffs as a means to persuade the plaintiffs to take an otherwise inadequate settlement. The plaintiffs would nonetheless be very much aware of it.

The proposals to settle the claim came from the plaintiffs’ lawyers. It was their initiative, prompted by the judge. The figures they proposed, accepted by the Department of Health, were those they felt would be acceptable to their clients (though, again, it needs to be said that there was no representative of the Scottish claimants on the steering committee, nor amongst the counsel putting forward the offer to settle). Accordingly, there is no criticism which arises in respect of either party from entering into the terms of settlement – the appropriateness (in the context of this particular litigation, and the legal bases on which it was advanced) of the amounts ultimately agreed remains a matter between the plaintiffs and their advisers, who under the collective arrangements they had agreed to operate (so it would appear) had recommended it. The real vice is that people were forced to litigate at all, rather than being offered – without the need for litigation – that proper compensation which they are yet to receive.

There was a suspicion amongst some that the announcement of a settlement in Parliament before the plaintiffs had a chance individually to consider both the details of the proposals and the advice of their lawyers “bounced” them into a position which made it difficult for them to refuse the settlement. There is some force in this, but it does not lead to the conclusion that the Government, or the Secretary of State at the time, were taking steps to ensure that the plaintiffs entered into a settlement which represented a poor deal for them. The reason for the pre-emptive announcement by William Waldegrave was that he thought that a public announcement that the Government was prepared to deal would help to secure the steering committee’s agreement. His approach was questioned at the time, both by the Chief Secretary and Number 10 officials who proposed an alternative form of words for Prime Minister’s Questions, and left it to the Prime Minister’s judgement. The Prime Minister accepted William Waldegrave’s proposal but told the Inquiry that “*I did not wish for a backlash that it had been imposed on a take-it-or-leave-it’ basis.*”<sup>211</sup> It was not known then, as it is now, that the prospects of survival of many of the plaintiffs were to improve dramatically.

## The waiver

The evidence before the Inquiry shows that a large number of people who had been infected with Hepatitis C had not been formally diagnosed by the time the settlement was entered into. They were unaware that they were infected with Hepatitis C. The references to hepatitis in the Master Statement of Claim were not there to claim that having that disease justified an

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210 Letter from David Watters to William Waldegrave 22 January 1991 DHSC0003657\_011

211 Written Statement of Sir John Major para 3.38 WITN5284001



award of compensation – they were there to help make a case that self-sufficiency should have been achieved, and then to argue that if it had been, this would have avoided the risk of the UK importing other blood-borne viruses from blood products manufactured abroad, where they had been made from donor populations amongst which different serious viruses might be circulating. They may have allowed for arguments that more should have been done to inactivate viruses, or greater care should have been taken to select donors. But they were not the foundation for any claim for “damages for hepatitis”.

Those for whom the Government bore ultimate responsibility – prescribing and treating clinicians and blood services – **did** know that certain patients had tested positive, and that it was highly likely that most or all had been infected with Hepatitis C although the patients themselves did not.

It is recognised generally by the law that where a claimant does not know that they had suffered damage for which they could claim, time should not tell against them so as to remove their right to sue. They should be entitled to make a claim from the date they had knowledge.<sup>212</sup> Those plaintiffs who had actually suffered infection with Hepatitis C, and did not themselves know of this, whilst in many cases their treating doctor or hospital did (because it had tested them) but had not told them, would, by entering the waiver, have been surrendering a right to come before a court, later, to explain that they had not known, and that it would be reasonable now to allow them to sue.

Some form of waiver was contemplated from the time that settlement was reached in principle. It was reflected in every draft which followed, although it was only in the later drafts that the word “hepatitis” appeared. The final wording was indeed that which was put forward by the plaintiffs’ side. However, this avoided what might have been a wider exclusion preventing suing for many other conditions. There was, therefore, potentially some good reason for it: it was only to apply to hepatitis infections, and not be so general as to prevent claims for other as yet unknown or unspecified viruses.

There can in very general terms be no objection to parties seeking to agree a waiver – for it is public policy to avoid a multiplicity of litigation arising out of the same set of facts. However, the way that policy is normally articulated is that a plaintiff (or “claimant” or “pursuer”) must bring forward against a defendant all the claims of which they are aware or ought reasonably to have been aware which arise out of a set of facts and circumstances, and relate to that defendant. It would thus not have excluded claims later made by plaintiffs who when they settled their claims in respect of HIV were unaware of their Hepatitis C infections, provided a judge later considered that they did not know, nor ought they to have been aware, that they

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212 The Limitation Act 1980 provides that defendants to actions for personal injuries can argue that the claim against them should have been brought earlier if more than three years have elapsed since the date of knowledge of the claimant. Section 14 of the Limitation Act 1980 provides that a claimant will only be deemed to have knowledge once they are aware of having a significant injury; that it is attributable to the act or omission of (in this case) a medical professional or body; and the identity of the defendant. The date does not depend on the actual knowledge of the claimant, but time “runs” from the date on which they could reasonably have been expected to suspect that there might be an issue, and to begin investigations.

had suffered from such an infection. The policy is subject to an overall judgment as to where the interests of justice lie – in general that will favour all the claims from one incident or set of events being heard together, but it does allow some discretion to the courts. However, if the principle is put into a contract, then the law will generally be prepared to give effect to that contract according to its terms, since it is what two competent parties have openly agreed. A waiver, once signed, is effectively just such a contract where it is entered into to secure a benefit which would otherwise be withheld.

It follows, here, that there may (strictly speaking) have been no need for the defendants to protect their position and the positions of those for whom it felt responsible by insisting on a waiver. The general law would usually produce the same effect, unless justice required a further claim arising out of the same facts to be litigated. But entering into a waiver does ensure that the parties are aware that if they have a claim they must abandon it, and sign the waiver; or pursue it, and decline to sign.

What is critical in terms of the justice of each case is the awareness of the potential claimant as to whether they had a claim – either their actual knowledge, or an awareness they ought reasonably to have had.

There was no clear evidence available to the defendants at the time that people who had been infected before 13 December 1990 with non-A non-B Hepatitis, or with Hepatitis C once that had been identified as such, knew of their diagnosis or, if they did, knew sufficient about it to understand both the nature of the infection and its potential severity. Both nature and severity were apparent to clinicians and medical advisers at the time. The general evidence to this Inquiry is that few, if any, of those infected had been told enough for them to be in a position to understand the importance of what they might be signing away. In general, they had not been given enough information for them to be able properly to exercise an informed choice whether they should sign or refuse to sign the waiver. It follows that to insist, by relying upon the waiver, that a person who had suffered hepatitis as a result of being infected (and had probably been infected before 13 December 1990) could not sue for being infected with hepatitis would be unfair. Fairness would demand that the infection and its consequences be known of in broad terms if further proceedings in respect of them were to be excluded.

What is fair necessarily depends on an individual assessment, case by case. There may be some who signed the waiver who did know enough (or ought, reasonably, to have known enough) to have sued, just as there will be many, almost certainly likely to be the majority, who did not.

It may well be that both the defendants' and plaintiffs' legal advisers worked on an assumption that people infected before 13 December 1990 knew that they had been infected, and what that infection implied for them, at least sufficiently to know what they were or might be surrendering by agreeing to a waiver: but there is no clear evidence of such an assumption, although it might be inferred from the fact that the final wording was first proposed by the plaintiffs' lawyers. However, it is much clearer that since all plaintiffs had to agree to the terms

of settlement, and each had to sign a formal waiver to get money which was critical to many because of their straitened circumstances, they were, as a matter of fact, under pressure to accept the terms. The pressure was produced by circumstances which ultimately were the responsibility of the clinicians and defendants in the action.

There is no record which clearly sets out the reasons for the terms of the Macfarlane Special Payments Trust<sup>213</sup> excluding English and Welsh plaintiffs making future claims in respect specifically of hepatitis as well as HIV. There is no record which clearly sets out the reasons for the terms not doing so in the case of the pursuers in Scotland. Most surprisingly of all there is no record setting out clearly why the provisions differed across the border. The lack of clearly articulated reasons for including a term which I have described above as unfair in the majority of cases in England and Wales reinforces my overall conclusion that its inclusion there was indeed unfair, at least without a term providing that the courts should have a discretion to permit cases to proceed where it would be unjust not to do so.

In conclusion:

- (a) The “line” taken by the Department of Health, as a collective view, in response to the claims unreasonably claimed too much.
- (b) The settlement was an agreement by the Government to a proposal put forward by the plaintiffs’ team of counsel, which the Government then accepted. The timing of an announcement of that settlement in principle created a pressure to accept its terms, but it was not intended to be unfair to plaintiffs for whom the Secretary of State for Health at the time expressed considerable sympathy, and it was open to the steering committee, having consulted with their clients, to take a view which differed from that of the plaintiffs’ counsel.
- (c) Those who pursued claims in Scotland should have been consulted. Whether there might have been liability in law would have been determined on many issues which arose on a UK-wide basis in respect of a time when administration was not as devolved as it is today – but the legal systems were distinct; some issues (for example self-sufficiency) would have had less traction in Scotland; and the costs regimes under which litigation was conducted and the level of awards given in the courts were not completely identical. However, particularly when the negotiations had been conducted by members of the English and Welsh bar without instructions from a steering committee which included any Scottish representation, the approach of accepting the plaintiffs’ offer made in respect of the English and Welsh cases and then seeking to apply it to Scotland called at least for some involvement of the Secretary of State for Scotland through whom any particularly Scottish perspectives might be addressed.<sup>214</sup>

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213 The payments were made through the Macfarlane Special Payments Trust No.2. See the chapter on the *Macfarlane Trust*.

214 When he gave evidence orally, Lord Waldegrave was asked about his knowledge of the litigation elsewhere than in England and Wales. He responded that “*There were constant discussions between ministers in live time, not annotated anywhere, there were discussions that take place outside Cabinet*”

- (d) The waiver was in terms equivalent to those put forward by the plaintiffs' lawyers, but I must answer the question posed by the terms of reference by saying that (although apparently agreed between the parties, who took time to consider the terms of which this was part) it was in the cases of most of the plaintiffs inappropriate for the defendants to seek a contractual exclusion of liability for hepatitis rather than leave it for a judge later to rule in individual cases if a claim for hepatitis could properly be brought.<sup>215</sup> Though a waiver was appropriate for claims in respect of HIV, it is difficult, too, to avoid thinking that there was little or no practical need for any such waiver in respect of hepatitis, given that it was unrealistic to expect plaintiffs to join together to sue in respect of hepatitis without there being adequate funding to do so, coupled with the demands of litigation upon individuals which many plaintiffs will already have realised from their experience with the HIV litigation could be draining.

Ben James, who was infected with HIV as a result of his treatment with blood products and had become involved in campaigning for compensation, wrote to the then Prime Minister, Margaret Thatcher, on 14 November 1989 in these terms:

*“Even though as I have stated the fault lies with successive governments, it is up to your government to show the minimum of honour and to reach a rapid settlement out of court to compensate myself and my fellows for the damage that has been done to us and our families. No monetary figure can justly be said to equal a life but to remove the financial burden from the victims and their dependents would go some way to enhance the remnants of their lives.”*<sup>216</sup>

The settlement that was reached was not rapid. And it did not – and did not purport to – compensate people for the damage which had been done to them. It did not remove the financial burden from them. Ben's own view of the settlement was apparent from a letter he wrote to his solicitors in January 1991: *“No doubt you received my reluctant acceptance of the Government's pitiful offer, or our pitiful offer to the Government.”*<sup>217</sup> Eighteen months later, in July 1993, Ben died.

The reality is that *“the Litigation was a blunt instrument in the attempted righting”* of the wrong done to people through infecting them with HIV.<sup>218</sup>

This consideration of the HIV litigation falls to be considered as part of the Government's overall response to so many patients receiving infected blood products, and also infected

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*were often crucial, where you met colleagues. So I cannot remember any such, but I'm sure that we were not all mute.”* Lord William Waldegrave Transcript 5 July 2022 pp136-137 INQY1000220. Though I accept that it is possible that there were discussions in passing about the Scottish litigation, it remains the case that there is no documentary evidence of this or contemporaneous reference to anything that might have been said in such exchanges. In the absence of this, the only conclusion to which I can properly come is that most probably the Secretary of State for Scotland was not involved in expressing the Scottish perspective on the settlement at any formative stage of policy relating to it.

215 If it arose out of essentially the same facts, against the same defendant(s) as the settled claims for HIV infection had done.

216 Written Statement of Rosemary James para 111 WITN5541001

217 Written Statement of Rosemary James para 117 WITN5541001

218 Second Written Statement of Mark Mildred para 12.3 WITN5258003

blood. It is appropriate in that light that the final words come from a press release issued by the solicitors making up the plaintiffs' steering committee on the day of the Prime Minister's announcement in 1991 in the House of Commons: "*These figures reflect the legal hurdles which the Plaintiffs must surmount in their litigation against the Government ... The figures do not represent proper compensation in moral terms for this appalling tragedy – that is not their purpose.*"<sup>219</sup> It would be 32 years later, almost to the day, that Parliament was informed that the Government accepted the moral case for compensation to be paid.<sup>220</sup> As at the date of writing this Report, compensation still has not been paid.

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219 Plaintiffs' Steering Committee Press Release *HIV Haemophilic litigation* 11 December 1990 DHSC0003654\_029

220 Commons Hansard: Infected Blood Inquiry Jeremy Quin, Paymaster General and Minister for the Cabinet Office, 15 December 2022 Column 1250. See also the Inquiry's Report on Compensation. Infected Blood Inquiry Second Interim Report 5 April 2023 p2 INQY0000453

## 6.3 Macfarlane Trust

This chapter looks at problems in the way in which the Macfarlane Trust was set up and run, and at problems in the way in which it was funded over the years by the Department of Health. It examines the attitudes of trustees to beneficiaries, and beneficiaries to trustees, and how the process by which individuals could access grants lacked clarity.

### Key Dates

**March 1988** Macfarlane Trust established as a charitable trust.

**1999** Trust's strategic review identifies that many beneficiaries are living below the poverty line.

**2003** Trust has some level of financial security for the first time in 14 years.

**2003** Long-term review (*A Full Life – Not Just Existence*) commissioned by the Trust suggests approaching the Department of Health for further funding.

**November 2005** Trust puts business case to the Department of Health based on long-term review, seeking funding of £7 million per year.

**June 2006** Trust's business case reaches the minister's office.

**July 2006** Department of Health offers an increase of £400,000 in response to business case.

**2009** Department of Health announces annual payments following the Archer Inquiry.

**2013** Katie Rendle reports on beneficiary/trustee relations.

**2015** APPG publishes a report identifying failings of the Trust and other Alliance House Organisations (AHOs).

**2017** replacement of the Trust and other AHOs by four national support schemes.

### People

#### Chairs

**Reverend Alan Tanner** (1988 - 2000)

**Peter Stevens** (2000 - 2007)

**Christopher FitzGerald** (2007 - 2012)

**Roger Evans** (2012 - 2016)

**Alasdair Murray** (2016 - 2018)

#### CEOs

**Wing Commander John Williams** (1988 - 1997)

**Ann Hithersay** (1997 - 2003)

**Martin Harvey** (2003 - 2013)

**Jan Barlow** (2013 - 2018)

### Abbreviations

**APPG** all-party parliamentary group

**MSPT1** Macfarlane Special Payments Trust No. 1

**MSPT2** Macfarlane Special Payments Trust No. 2

**NSSC** National Support Services Committee, Macfarlane Trust

## The origins of the Macfarlane Trust

It is critical to understand the rationale underlying the Alliance House Organisations.<sup>221</sup> To do so, one has to ask: how did this all begin? The place to start is the first of the Alliance House Organisations to be set up: the Macfarlane Trust.

*The Initial Government Response 1985-88* has described how the Government first responded to what had happened by taking the view that nothing had been done wrong; that compensation would only be paid where fault was established in court, and that to depart from that principle would be to begin to slide down a slippery slope to no fault compensation. This, it thought, was to be resisted. The very particular hardships which had been caused by being given infected blood products became the subject of campaigning by *The Northern Echo*, the Haemophilia Society, the media, and some MPs, such that in 1987 there was a turnaround in the government position. It still maintained that compensation should not be given, but now accepted that some form of payment should be made to those infected with HIV and their families on an ex-gratia basis. To distance government from decisions as to how best to disburse a limited fund, it was at first intended that £10 million be given to the Haemophilia Society for it to distribute. That idea then developed into setting up a charitable trust – the Macfarlane Trust – independent of government, as charities are. The sum of money allocated to it at the outset was not calculated by reference to losses, nor to needs of the beneficiaries – the account of how the Trust came into being shows that it was, rather, a response to media pressure and a feeling that the Government needed to be seen to be doing something to alleviate the dreadful position in which people with bleeding disorders who had HIV and their families had found themselves.

Less than two weeks after John Moore, the Secretary of State for Health and Social Security, met a delegation from the Haemophilia Society (as described in the chapter, *The Initial Government Response 1985-1988*) it was announced in Parliament that an ex gratia grant of £10 million was to be made to the Haemophilia Society for it to distribute. Following the announcement in Parliament that an ex gratia payment would be made, and the evolution of that to become the initial capital for a charitable trust, a trust deed was entered into on 10 March 1988. The initial trustees were Reverend Alan Tanner, Clive Knight, Vera Demmery and Alan Palmer. The purposes were charitable. Money (the £10 million) paid by the government was to be subject to the terms of the Trust. Its objects were:

*“to relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United Kingdom are suffering from Acquired Immune Deficiency Syndrome or are infected with human immunodeficiency virus and who are in need of assistance or the needy spouses parents children and other dependants of such persons and the needy spouses, parents, children or other dependants of such persons who have died.”<sup>222</sup>*

221 What became known as the Alliance House Organisations consisted essentially of four bodies, the Macfarlane Trust, Eileen Trust, Skipton Fund and the Caxton Foundation. Each has its own chapter in this Report.

222 Trust Deed constituting the Macfarlane Trust 10 March 1988 clause 4 p5 MACF0000003\_064

Two features of this provision deserve to be highlighted. First, the class of beneficiaries was not restricted to those who had been directly infected. It specifically included spouses, parents and children (including the spouses, parents and children of those who had died)<sup>223</sup> and even went so far as to include a class of people (“*other dependants*”) who did not necessarily have any immediate familial relationship. Second, “*need*” was not defined as financial need, nor was “*assistance*” specifically limited to the provision of money. Indeed it is plain that it was capable of extending beyond a grant or payment of money. The terms of the then clause 5 gave the trustees power to provide holidays, assistance in kind, shelter, housing or other accommodation (whether temporary or permanent) and to:

“(ii) *promote the education of and provide scholarships and apprenticeships for children and young persons who are in need ...*

(iv) *do all such other lawful things as may be calculated to further the attainment of the above objects PROVIDED THAT nothing herein contained shall permit or be deemed to permit the doing of any thing or the pursuit of any purpose which are not exclusively charitable.*”<sup>224</sup>

There was thus a wide range of matters which might fall within the heading of “*need*”, with the restriction that whatever that need was had to be charitable if it were to be relieved by use of the Trust funds. However, despite this width, the way in which the words “*charitable need*” were interpreted during the life of the Macfarlane Trust became something of a fetter upon the assistance which the trustees might otherwise have felt it appropriate to give.

The width of the class of beneficiaries<sup>225</sup> is emphasised by the fact that the inclusion of a bereaved group wider than that of spouses or partners has not been replicated in current infected blood support schemes.

Under clause 10 of the deed, six more trustees were to be appointed, bringing the total to ten. Of the total of ten,<sup>226</sup> six were to be appointed by the Executive Committee of the Haemophilia Society, and four by the Secretary of State for Social Services.

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223 Thus making good the promise contained in the statement to Parliament, when the payment was announced, that the sum was to enable the making of payments “*to the affected individuals and families throughout the United Kingdom*” (emphasis added). Extract from Hansard parliamentary debate on Haemophiliacs (Financial Assistance) 16 November 1987 p1 LDOW0000241. As the text records, the Trust deed went further even than this by including “*other dependants*”; though it is questionable how far this resulted in support actually being made for families affected, it is the case that in his evidence Christopher FitzGerald said that “*we were extremely conscious of the fact that we were not – not only were we not doing as much as we would really want to for primary beneficiaries, we **certainly** weren’t doing as much as we wanted to do for the other beneficiaries*” (emphasis added). Christopher FitzGerald Transcript 26 February 2021 p9 INQY1000101. The inference from this is that it was not that the trustees were unwilling, it is that resources did not permit them to do as they would have wished.

224 Original emphasis. Trust Deed constituting the Macfarlane Trust 10 March 1988 clause 5 pp5-6 MACF0000003\_064

225 As provided for by the deed – though a number of family members had the legal status of beneficiary, in practice they saw little or no actual benefit.

226 By an amended deed in 2012 the number reduced to nine.



Amongst those appointed by the Haemophilia Society was Peter Stevens,<sup>227</sup> who was a trustee from 1988 until 1992, then again from 1999 when he was invited to rejoin the board of trustees in order to become chair. He remained chair until 2006.

The establishment of the Macfarlane Trust to provide charitable discretionary payments to those who were in need was followed by the two separate special payments trusts intended to benefit the same group of people – those who had haemophilia who had become infected with HIV through their treatment with blood products – by providing non-discretionary payments. The Macfarlane Special Payments Trust No. 1 (“MSPT1”) provided for £20,000 lump sums to be paid to those infected and some dependants of now deceased infected persons.<sup>228</sup> In 1991 this was supplemented by the Macfarlane Special Payments Trust No. 2 (“MSPT2”) which provided for payments ranging from £21,500 to £60,500 according to individual family circumstances. Whereas the creation of a charitable Macfarlane Trust was a response to the campaign which the Haemophilia Society had orchestrated, these two trusts were a response to the litigation brought by nearly 1,000 patients.<sup>229</sup>

Several witnesses criticised the way in which the Macfarlane Trust was set up as one which was certain to cause problems or was designed to fail, and told the Inquiry that the seeds of later dissatisfaction and difficulty amongst the beneficiaries were caused by this. Peter Stevens was particularly scathing. In an interview in 2007 with Russell Mishcon he said he considered the Trust was a “*short term fix*”.<sup>230</sup> Speaking of the Government he said: “*I think they were caught out by the lack of favourable response, which was why they then introduced the two capital payments and then, at that stage, I think they thought: ‘Well okay that’s done and dusted, these people have only a couple more years to go and we’re off the hook.*”<sup>231</sup>

In evidence he said: “*They gave us what they thought they could afford and what they could get away with*”,<sup>232</sup> and “*setting up an inadequately funded charity was the Government’s view of what to do about the people.*”<sup>233</sup>

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227 Peter Stevens was also chair of the Eileen Trust from 1999 to 2017 and a director of the Skipton Fund until 2017. He gave evidence to the Inquiry covering at first hand the early days of the Macfarlane Trust, the period of his chairmanship, the setting up of the Skipton Fund, and his time as chair of the Eileen Trust. Written Statement of Peter Stevens WITN3070003, Peter Stevens Transcript 23 February 2021 INQY1000098, Peter Stevens Transcript 24 February 2021 INQY1000099

228 The Macfarlane Special Payments Trust Report and Accounts December 1991 HSOC0013352

229 See the previous chapter.

230 Interview with Peter Stevens 20 December 2007 p2 MACF0000030\_006

231 Interview with Peter Stevens 20 December 2007 p2 MACF0000030\_006. The view that the fund was set up in the expectation that the number of beneficiaries it served would soon dwindle has been repeated from a number of sources. It would certainly have accorded with the view in 1987 of the likely life expectancy of anyone suffering from HIV infection. However, the view that offering support by setting up the Macfarlane Trust was a cynical move to buy-off criticism in the law courts or the courts of public opinion because it was always intended to be short-lived does not explain why the beneficiary class should have been set so widely that it was likely to last for at least a generation. It could well have lasted longer still.

232 Peter Stevens Transcript 23 February 2021 p77 INQY1000098

233 Peter Stevens Transcript 24 February 2021 p20 INQY1000099

Christopher FitzGerald, chair of the trustees from April 2007 to April 2012 in succession to Peter Stevens, contrasted the commitment of the Government as expressed when the Macfarlane Trust was set up with the funding actually delivered. He commented that “*it was very disappointing*” that the Government had not taken the opportunity given by the Archer Inquiry to “*put right what they had not got right all those years before*” (that is, that it should by then have avoided making payments on a discretionary basis).<sup>234</sup>

## Problems caused by the way in which the Macfarlane Trust was established

Even if the Government had been right in its conclusion that no wrong had been committed against those who suffered infections from NHS treatment,<sup>235</sup> there were at least five central problems which arose from the way in which the Trust was set up.

First, the basis for the ex gratia payments was in recognition of those who already faced a lifetime with the haemophilia with which they were born; on top of that, they had the additional difficulties caused by HIV, which gave rise to exceptional levels of hardship. That was accepted. But no detailed assessment of the particular financial impacts was made at the time; the Government never intended to meet all or most of the needs or to address the true extent of the financial impacts. Without this, whether any particular sum of money was appropriate was pure guesswork, and the amount provided was always likely to fall far short of need.

A similar point arises in respect of MSPT1 and MSPT2. They could be seen as responses to exactly the same needs within the succeeding three years.<sup>236</sup> The sums appear to have been assessed by making guesses as to need on the one hand (whilst recognising that what had been paid thus far was insufficient)<sup>237</sup> and on the other by knowledge of the sum which the Government wished to pay at the time in response to pressures on it to pay something more. This in turn led to an inevitable feeling that what happened between 1988 and 1991 had been closer to a reluctant sop to opinion than it was to a genuine attempt to relieve need.<sup>238</sup>

Second, the Macfarlane Trust was set up as a charity. As a response to those who were complaining that they were entitled to recompense because the NHS and government had done them wrong, the fact they had to seek charity was likely to lead to many who had pride

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234 Christopher FitzGerald Transcript 26 February 2021 pp133-134 INQY1000101

235 Which, for reasons set out in this Report, it was not.

236 However, the payment of these sums was made on a different basis. MSPT2 was intended to provide fixed sums of money to those claimants whose claims in the HIV litigation had been settled, whereas the Macfarlane Trust was to provide sums to meet particular cases of hardship on a discretionary basis: the money from both may have been spent meeting the same needs but the payments from each thus had a different rationale.

237 If it had been thought sufficient there could have been no adequate and proper basis for making further payments out of government funds, unless it were thought that the settlement of the litigation required it.

238 Looked at purely as a matter of arithmetic, the sums thought appropriate for relieving hardship whilst avoiding compensation had grown by a factor of seven over just three years.

in what they had achieved in life, despite the challenges of haemophilia, feeling they had been reduced to holding out a begging bowl.<sup>239</sup>

Third, it was unclear what assumptions were being made about future needs. Witnesses repeated the view that the Government expected the Trust to operate only for a short while: the natural progression of HIV infection in 1987 was that death would almost inevitably follow, within a few years. But the Macfarlane Trust deed provided for a much wider class of beneficiaries than those who were infected. Though the sacrifices of career and income and the toll on the mental health of those who were principal carers for, or family members of, a person infected with HIV have become clearer, they ought to have been in contemplation even then. Yet there was no assurance built into the scheme that any additional funds would be provided to meet such needs although they would be ongoing for the foreseeable future. The endowment of a charitable fund might conventionally be by the settlement of a large lump sum upon trustees, in the expectation that if it is invested the income produced will be sufficient to make any necessary payments. It has to be large enough to do so, for otherwise capital will begin to be used up to fund outgoings, and in turn the reduced capital will produce less income, leading to an increasing rate of capital attrition. Broadly, this is what happened. It led inexorably to the trustees being cautious about how much money they could allocate to grants in any particular year since there was no sufficient assurance of further funding. The creation of a reserve to accommodate this caution in itself led to further difficulties since many beneficiaries, not unreasonably, saw their requests being limited, or denied, when they could have been easily met out of the reserve. What must have seemed to them an ample capital sum was simply not being spent to alleviate those needs which they knew to exist from personal experience.

Fourth, the lack of funds became ever more apparent over time as treatment improved, and the deaths that had seemed inevitable became less and less imminent. In 1987 when the scheme was originally announced, few expected many – or indeed any – of those infected to survive for long, though some opportunistic infections which formed part of the spectrum of those which in combination amounted to AIDS could be individually treated, at least for a while. By the mid 1990s, highly active antiretroviral treatment (“HAART”) was found to be effective for most, even though it did not eliminate the virus.<sup>240</sup> Those who had been infected now faced the problems of survival, after or with continuing illness and treatment, rather than the problems of anticipated imminent death which had so affected their lives until then. They were growing older, and with them their loved ones, upon whom many of the strains

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239 The Government set the Trust up as a charity, a body which was outside of government, because it “keeps direct Government involvement to a minimum”: this was consistent with its position at the time that it was not directly responsible for people with haemophilia becoming infected; see Tony Newton’s rationale as set out at: Memo from Tony Newton to the Secretary of State 26 August 1987 DHSC0004541\_079. In addition to his minute to the Prime Minister of 30 October 1987 and a memo from John Moore to the H(A) Cabinet Committee of 4 November 1987: Memo from Tony Newton to the Prime Minister WITN0771209, Memo from the Secretary of State for Social Services on special financial assistance for haemophiliacs 4 November 1987 CABO0100001\_002

240 As at the date of writing possibly three people throughout the world have been thought to have cleared HIV from their system. To appreciate how small a percentage this is, it can be visualised as little more than three grains of sand on a sandy beach.

of coping financially, physically, emotionally, educationally and socially had already fallen. A model of distribution of funds intended to meet one set of circumstances had now to be adapted to something radically different. Even with inspired leadership and stewardship this would have been a challenge for the trustees, since there was no assured source of funds. Nor of the minimum level of funds that was needed. Unfortunately the Macfarlane Trust did not have such leadership from their chairs and CEOs (though Christopher FitzGerald and Ann Hithersay together with some individual trustees are to be excluded from this particular criticism, and Alasdair Murray took over as chair too late to make an impact in this respect).

Fifth, the charity was small by comparison with many grant-making bodies. Its staff was thus always likely to be small. A particular disadvantage of small staff numbers is the vulnerability of the enterprise to the absence or illness of any staff member. Jan Barlow, in her evidence covering her term of office as chief executive of the Macfarlane Trust (January 2013 to October 2018), identified that there had been a staffing cap placed on the Macfarlane Trust.<sup>241</sup> There is no other evidence, oral or documented, which supports the existence of such a cap,<sup>242</sup> but the practical consequence of small numbers remains the same – that with limited staff numbers, the Macfarlane Trust did not have access to a ready reserve workforce who might step in if others fell absent and it would find it difficult to fundraise easily.<sup>243</sup>

In submissions to the Inquiry, the Haemophilia Society neatly encapsulated most of these problems; it said: *“these organisations were never sufficiently funded, or given any reassurance of the long-term support needed for the community, or even considered the community and the impact of infection.”*<sup>244</sup>

Whereas administration by government itself would have had the potential to avoid the disadvantages set out above, it might have made it less likely that innovative means of support beyond the payment of funds would be provided. As an independent charity the social needs of beneficiaries could arguably be satisfied more easily than if it had been directly

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241 Jan Barlow Transcript 2 March 2021 pp24-25, p47 INQY1000102

242 If the “cap” was a real one, as Jan Barlow’s evidence suggested, rather than a graphic way of expressing practical limitations, evidence of this is to be expected.

243 There was substantial evidence that staff illness had caused difficulty: for instance, Martin Harvey fell ill towards the end of his period in office as CEO; and before that Jude Cohen had lacked the support she needed for her tasks because another member of staff was ill.

244 Closing Submissions of Haemophilia Society 16 December 2022 p193 SUBS0000065. Thompsons solicitors on behalf of their clients (largely in Scotland) expressed the same but added additional points, which are well-founded. It described the Alliance House Organisations as *“an inadequate attempt on the part of government to provide financial support to the infected and affected. That they were was not surprising in that they were all formed as a sticking plaster in circumstances where the State had carried out no assessment at all of the needs or losses of the community whom they were ostensibly designed to support. Thus, the money provided for them (whether discretionary or not) was always inadequate both in amount and in the category of individuals who were able to claim – the affected being almost entirely excluded, the harm to them never having been addressed or assessed either. The purpose and objectives of the schemes was [sic] poorly defined. For these to have been clearly stated would have required a clear engagement of why the monies were being paid, engagement with the issue of the moral duty of the State to make the payments and its basis and extent and an assessment of the losses and needs of the infected and affected. That there was no clear definition is a clear indication that there was no clear purpose.”* Written submissions on behalf of the core participant clients represented by Thompsons Scotland 16 December 2022 p1162 SUBS0000064

administered. Some efforts were made towards this. The involvement of beneficiaries with those running the scheme could also be facilitated.<sup>245</sup> One means by which it was sought to do this was by setting up a user group (in the Macfarlane Trust known as a Partnership Group).<sup>246</sup> The Macfarlane Trust also provided the services of a dedicated social worker (initially Tudur Williams); and the services of an independent financial advisor (from 1990/91 until 2005/06 when Susan Daniels operated in that capacity). Of particular help to many beneficiaries, and much appreciated, was the funding by the Macfarlane Trust of the work of Neil Bateman, who was engaged as a contractor to assist with and advise on welfare benefits from around 2007 onwards.<sup>247</sup>

The most obvious reason for using the Macfarlane Trust as a vehicle was not, however, a balance between the pros and cons of that model compared with an “in-house” solution. Rather, as the 1987 memorandum to the Cabinet Sub-Committee had in effect set out, it lay in providing a short-term, one-off answer to a campaign which it was embarrassingly difficult to answer and by keeping the charity at arm’s distance from government, effectively ensuring that any beneficiaries disaffected by the way the grant system operated would blame the Trust and its administration rather than government.<sup>248</sup>

The special payments in settlements of the legal case brought by nearly 1,000 people with haemophilia<sup>249</sup> were given to the Macfarlane Special Payments Trust No.2 to administer since it already knew who the beneficiaries were, and because its ready contact with them meant it was a convenient means of making these payments – but this too kept the settlements at arm’s length from the Government.

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245 It is not impossible for a directly administered scheme to do this, but probably more easily achieved by an independent charitable body.

246 Though this in the event had a chequered history, the reasons for its stuttering contributions owed more to other factors dealt with later. They were not inherent in the nature of partnership groups.

247 Much of what follows is critical of the Macfarlane Trust. However, the picture is not all one-sided. Neil Bateman, an impressive witness, said in his written statement: “*I was given complete freedom to represent clients and to be a vigorous advocate against the DWP [Department for Work and Pensions] and local authorities. Many charities, especially those with links to government, get anxious about ‘not upsetting’ government departments, but it is a tribute to those charities that they always fully supported my work on behalf of beneficiaries.*” Written Statement of Neil Bateman para 19 WITN3487001. He confirmed those words in his oral evidence and added that he always found the Trust very supportive, and they were fully aware of what he was doing. Neil Bateman Transcript 12 March 2021 p123 INQY1000109

248 Memo from the Secretary of State for Social Services on special financial assistance for haemophiliacs 4 November 1987 p4 CABO0100001\_002. Tony Newton’s preference for the option of the Haemophilia Society administering the money was expressed in the following terms: “*The second option I find particularly attractive as it minimises Government intervention; is consistent with our views elsewhere for helping people with particular needs outside the direct framework of social security; and would be consistent with our policy of not accepting direct responsibility for damage caused in this way.*” Memo from Tony Newton to the Secretary of State 26 August 1987 p2 DHSC0004541\_079. See also the chapter on *The Initial Government Response 1985-1988*.

249 Also paid to others who had not been plaintiffs but were in similar circumstances – all those who were people with haemophilia who had HIV in consequence of their treatment were included.

## Operation of the Macfarlane Trust

Matters of policy and direction were determined by the Board.

### Chairs

The first chair was Reverend Tanner. He also became chair of the Eileen Trust from its inception in 1993, and remained as chair of both until being replaced by Peter Stevens in 2000. He in turn was succeeded in 2007 by Christopher FitzGerald (Peter Stevens continued as chair of the Eileen Trust thereafter). Christopher FitzGerald retired in 2012 and after a short gap was succeeded by Roger Evans who had been a trustee of the Macfarlane Trust since 2006. Roger Evans remained chair until May 2016 when he, somewhat suddenly, resigned. By that time the continued existence of the Macfarlane Trust was under question. There were serious issues whether the Alliance House Organisations would continue at an arm's length from, though funded by, government or would thereafter be operated directly by the state. Alasdair Murray, who had been a trustee since March 2014, became chair whilst the writing was on the wall. He continued in that capacity until the Trust could no longer hope to function as it had done previously, and it transferred such assets as remained to the Terrence Higgins Trust, to be operated by that trust thereafter as a designated ring-fenced fund.<sup>250</sup>

The chairs were unpaid, and worked part-time.

### Day-to-day running

The day-to-day running of the Trust was allocated in 1988 to an “administrator”, a position occupied by Wing Commander John Williams until 1997 when Ann Hithersay took over, and became known as the chief executive. This title better described her role. She retired in October 2003 to be succeeded by Martin Harvey. Martin Harvey's later time in office was bedevilled by illness, and for a period of time before 2013 the Trust functioned without an active chief executive. It was then (from January 2013) that Jan Barlow succeeded. She became chief executive of both the Macfarlane Trust and the Caxton Foundation,<sup>251</sup> and stayed in post until October 2018, by which time both ceased operating.

Reverend Tanner, Wing Commander Williams, and Martin Harvey have died. The other named chairs or CEOs survive, and each gave evidence.

As explained further below, it is clear that opinions, attitudes and personalities affected the running of the Trust, the extent to which it made best use of its opportunities to serve the beneficiaries, and the satisfaction of those beneficiaries themselves. The disadvantages inbuilt by the ways in which the Trust was structured would have made the roles of chair and CEO difficult to fulfil, however talented the post-holder might have been, but in the event were not remedied to the extent they might have been. They were, rather, accentuated.

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250 Written Statement of Ian Green p2 WITN3075008

251 See the chapter on the *Caxton Foundation*.

## Relations between beneficiaries and the Macfarlane Trust

The general view of the Macfarlane Trust given to the Inquiry by individual beneficiaries was reflected in the evidence of Susan Daniels. Her recollection appeared definite and clear and she gave it in a straightforward, compassionate and empathetic way. A particular value of her evidence was that it traced the operations of the Macfarlane Trust from 1990 until 2018 (though after June 2006, when she resigned from a role as caseworker for the Macfarlane Trust which she had occupied for a little over a year, she was more closely involved with the Eileen Trust to which she was then recruited by Peter Stevens). She described a change occurring in the early part of the 2000s. She put it this way in evidence:

*“When I first joined, or worked for the Trust in 1999 I found Tudur Williams<sup>252</sup> to be a very kind and caring person. I also found Ann Hithersay to be very caring. But after she left the Trust became – – it became almost – – the bureaucracy became much more. They seemed to have more and more people working there, more and more committees. It became much harder for the registrants to get grants. I think they were making ill people go through hoops to get ... a simple grant ... I think there was [a] total lack of compassion. Not with the junior staff, let me say that, that I got on very well with most of the staff – – the junior staff who worked in the office and they were all very – – most of them were very kind to the registrants. So I don’t want to say anything, you know, other than that ...*

*Q. Can you recall what the response to that was from senior members of staff and ... from the trustees?*

*A. I don’t think I got much of a response. I think they probably felt that I was a rather kind of over emotional woman and that they didn’t do anything about it.”<sup>253</sup>*

Her viewpoint on the Trust is independent: it was only briefly that she was an employee of the Trust, as a caseworker. She had become attached to working for the Trust because of her practice as an independent financial advisor. She was gradually asked to become involved with financial planning more and more though she regarded it more as debt counselling. She achieved considerable success on behalf of individual beneficiaries. She visited several at home. By October 2004 she was highlighting the plight of widows in a financial advisor’s report to the board. They did not have sufficient funds for everyday living. She commented: *“it does appear that the current trend is to reduce income to a base figure of approximately £100 per month. In many cases, this will lead to real hardship and ... very vulnerable people will be forced to seek funds from highly expensive and sometimes unscrupulous loan companies.”<sup>254</sup>*

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252 Social worker at the Macfarlane and Eileen Trusts.

253 Susan Daniels Transcript 10 March 2021 pp48-49 INQY1000107

254 Report of Financial Advisers for MFT Board meeting 5 October 2004 p1 MACF0000019\_119

During her time as caseworker, she reported to trustees on a visit she had had in Birmingham with a social worker.<sup>255</sup> She described how when she arrived to talk to a couple with a view to giving helpful financial advice it was clear that they were very nervous and one was “*visibly trembling when I arrived.*” She commented: “*It took them a little while to realise that I was there to help them deal with their problems not make them worse.*” In the last paragraph of her report to the trustees she commented: “*I feel deeply saddened, after all my years with the Trust and the excellent work it has done in the past, that it has now come to the point when registrants inform me that ‘The MFT [Macfarlane Trust] is a major stress point in my life’ and are frightened by the prospect of my visit.*”<sup>256</sup>

In another visit to Birmingham at about the same time to a different registrant, focussing on a request to repair a headstone for the registrant’s first wife who had died aged 33 having been infected with HIV, Susan Daniels commented that she had wondered whether “*compassion is still an objective of the Trust in dealing with its members*” and that “*Delaying a decision on somebody who is already in a highly stressful condition can be as bad as a poor decision, perhaps worse.*”<sup>257</sup>

By June 2006 she decided to resign. She did so because she felt unsupported by the recently appointed chief executive, Martin Harvey. She found herself suddenly being questioned for the first time about matters which she had been attending to for some 15 years without complaint; now she got constant emails asking why she had done this or that. She felt bullied. Peter Stevens later asked her to help him at the Eileen Trust, and Susan Daniels told the Inquiry that he then apologised and said she had been right on a lot of things that she had said at the time: she added that she had already left the Macfarlane Trust by then and just continued with the Eileen Trust.<sup>258</sup>

She found the Eileen Trust to have a totally different atmosphere from that she had experienced at Macfarlane: its registrants were, by contrast, treated with compassion; they were less angry than those who were beneficiaries of the Macfarlane Trust; it was considerably smaller; it was less bureaucratic. She commented specifically that the trustees “*actually spent time*” with the registrants.<sup>259</sup>

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255 The social worker, Mark Simmons, has come in for particular praise from a number of participants in the Inquiry.

256 Report to the Trustees on visit in Birmingham 5 August 2005 pp6-7 MACF0000113\_002

257 Report on the visit to Mr and Mrs [Anon] at Birmingham University Hospital 25 August 2005 p2 MACF0000101\_086. This has an echo in a powerful letter that a clinical psychologist, Dr Caroline Coffey, wrote on 11 March 2021. Though it concerned the Wales Infected Blood Support Scheme, and issues of parity of support across the home nations, its principal insight is from a professional expert perspective that: “*Understandably people report entrenched feelings of anger and injustice, alongside damaged identities related to feeling like ‘a second class citizen’, as unworthy and undeserving due to a growing awareness that harm was knowingly inflicted on an ‘unimportant’ group of people. The extent of psychological injury is unquestionable.*” Letter from Dr Coffey to Catherine Cody 11 March 2021 WITN4506014. Treated in a way which regularly and systematically delays responding to an urgent request for assistance not only is to be condemned of itself, but also because (accepting what Dr Coffey says) it causes further psychological harm to those already bruised emotionally by their experiences.

258 Susan Daniels Transcript 10 March 2021 pp101-102 INQY1000107

259 Susan Daniels Transcript 10 March 2021 p69 INQY1000107



The evidence given to the Inquiry shows that the sense of fear and distrust to which Susan Daniels referred was widespread, and not to be dismissed as the views of “*a rather kind of overemotional woman*” as she suspected it was.<sup>260</sup> It is not only reflected in a number of the written statements of witnesses who were beneficiaries, and many of the available documents, but also in the testimony of Jude Cohen, the head of support services.<sup>261</sup> She was clear in her evidence that there was a “*horrible undercurrent*” of distrust in both directions.<sup>262</sup> Many beneficiaries felt misinformed by and fearful of the chief executive; trustees generally<sup>263</sup> distrusted the beneficiaries. The climate of anxiety when approaching the chief executive (after 2004) was raised in a Partnership Group meeting. The record of the meeting shows that it appears to have been accepted by the chief executive and head of support services that there was indeed such a climate.<sup>264</sup> Concern was expressed about misinformation, delays in responding to grant applications, and that beneficiaries had no mechanism by which to communicate problems effectively to the trustees.

In November 2004, a month after these concerns had been registered at the Partnership Group meeting, a regional meeting was held at Birmingham. Jude Cohen gave a report of it to the National Support Services Committee (“NSSC”) (a sub-committee of trustees, with the function of determining grant applications). Her report again demonstrated growing hostility between registrants and the trustees of the Macfarlane Trust. A part of her specific function was to establish regional support workers in post. The beneficiaries considered they neither wanted nor needed them: the chief executive told attendees at the meeting that part of the regional support workers’ function was to carry out a financial review of their circumstances in order to determine need, which might include home visits. The view was strongly expressed by many attendees that they would not “*let an RSW [regional support worker] in the house*”.<sup>265</sup>

There is no material to show that the Macfarlane Trust actively addressed these reports of a growing loss of confidence. It did however take some steps in February 2005 to check whether its internal grant-making procedures were in accordance with best practice and appropriate to the Trust’s size and the nature of its grants. It asked Kingston Smith Chartered Accountants to review these procedures. Their report identified weaknesses in the system of authorising grants. Although it found that “*The majority of the procedures in place at the trust stand up well when compared with those outlined in the guidance*” issued by a variety of charitable bodies, it noted the Trust was least compliant with that guidance in monitoring and evaluation, without which it would be unable to answer the key question of whether it was helping those in the greatest need.<sup>266</sup>

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260 Susan Daniels Transcript 10 March 2021 p49 INQY1000107

261 She was in this role from 2004-05.

262 Jude Cohen Transcript 11 March 2021 p59 INQY1000108

263 Some more than others.

264 Minutes of Macfarlane Trust Partnership Group meeting 1 October 2004 p3 MACF0000019\_130

265 Head of Support Services Report 1 December 2004 p3 MACF0000107\_015

266 Report on the Grant Making Procedures of The Macfarlane Trust 18 April 2005 p5 MACF0000014\_001

Of greater relevance still to the growing problems of mutual trust, their report identified that consultation with the beneficiaries in respect of changes in funding was necessary; and that the Trust's application forms and literature "*should be clear and user friendly and should include ... what the trust will and will not support*" and include "*any upper or lower limits on grant size*".<sup>267</sup>

Jude Cohen's view was that this recommendation was not being honoured in practice. In a report to the NSSC for a meeting on 2 September 2005, she recorded that social workers and consultants had expressed unhappiness at late changes in policy in respect of respite grants, and that she had also "*received more and some much stronger verbal complaints*". She told the Committee that it was not following the recommendations of the Kingston Smith Report; attached correspondence from registrants complaining that they had not been informed of the grant-making policies; drew attention to unfairness, unhappiness and extra stress; and urged full publication of the details of those grants for which beneficiaries could apply.<sup>268</sup>

Shortly after this Jude Cohen was summarily dismissed.<sup>269</sup> The reasons given for this have differed, and (such as they are) are opaque. The process does not appear to have complied with basic employment standards.

Over the next six or seven years relationships remained strained. Katie Rendle, the sister of a beneficiary, had been told that relationships between trustees and beneficiaries were poor. Beneficiaries saw the board as paternalistic, opaque, and many of its members detached from the everyday realities of living with haemophilia and HIV. Since she had spent time working at the Charity Commission, and her brother was keen to understand what problems there were in the administration of the Trust, and whether improvements might be possible, she was interested in playing a part as a trustee. She had particular skills in communications.<sup>270</sup> When interviewed by the Haemophilia Society for a role on the trustee board as a "*user trustee*" (though she was not herself a beneficiary) she talked about her idea of conducting a survey to review the Macfarlane Trust's communications, with the aim of improving two-way communications between the Trust and its beneficiaries. She was appointed, and secured the board's agreement to conduct such a survey.<sup>271</sup>

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267 Report on the Grant Making Procedures of The Macfarlane Trust 18 April 2005 p14 MACF0000014\_001

268 Policy discussions briefing paper for the National Support Services Committee meeting 2 September 2005 pp2-4 MACF0000101\_079

269 Jude Cohen Transcript 11 March 2021 pp112-118 INQY1000108. She had not by then served long enough to mount a claim for unfair dismissal. Nonetheless, an employer trusted with public functions ought to comply with (at least) basic employment standards. It is impossible to know what the motive for the sacking might have been. She may have been seen as a complainer: the management ethos, generally, was one which resented complaints, and did not always accommodate minority (or critical) viewpoints easily. On the evidence available, however, I can draw no conclusions save that no good reason has clearly been shown for her dismissal, that no appropriate procedure was followed, and that the chief executive Martin Harvey was the person centrally responsible for her going.

270 Particularly digital communications.

271 Katie Rendle Transcript 11 March 2021 pp148-149, pp165-167 INQY1000108

263 beneficiaries completed the survey questionnaire. Katie Rendle reported her findings to the board in January 2013.<sup>272</sup> Some of the pictures painted<sup>273</sup> revealed telephone communication of a condescending tone, with phones left unanswered, or the relevant person being unavailable. Telephone manner was poor, and calls were not returned as promised. There was a sense that many people wished for more help. On the other hand, 68% rated phone communications highly (rating them 4 or 5 on a scale of 0-5). However, the evidence showed Katie Rendle that the standards of communication had dropped recently, and the remaining 32% gave a score of 3 or lower. The ratings were similar for written communications. Just under a third rated letters from the Trust as medium to poor, the main issues being that they seemed “*threatening, uncompassionate or patronising ... long and wordy ... too formal and unclear*”, and that they lacked explanation. As to communication by newsletter some of the issues raised were that the information was out of date, that insufficient notice of events was being given, there was insufficient input from beneficiaries, the topics were too inward looking and not useful enough to beneficiaries, and the design and layout was not optimised for people with visual impairments. As to communication by use of a digital forum, relatively few beneficiaries used this, though a core of users found it helpful. The website was not very well visited: some beneficiaries were even unaware that the Trust had a website, whilst others seemed to confuse it with the forum. Beneficiaries were however very positive about an idea that the website might include information about applying for grants, the way in which the Trust decided on applications, and how other sources of income and support might be accessed. Katie Rendle agreed in evidence that she understood that the current form of the website “*didn’t include that information or didn’t include sufficient information on those topics*”.<sup>274</sup>

Overall, around two thirds of beneficiaries reported that they did not receive enough information about grants. This lack of information caused confusion, frustration and led to delay. One of the strongest themes emerging from the survey was that there appeared to be a practice of withholding information from beneficiaries. More than half of those who responded complained that they had not been consulted about the way in which the Trust distributed its funds, and did not fully understand it.

Little seemed to have changed in the previous six years.

Armed with the material which the survey provided, Katie Rendle made a number of positive recommendations to the board.<sup>275</sup> Jan Barlow as chief executive was asked to take the next steps to action the recommendations of the report or to decide what to do with it.<sup>276</sup> Despite this, nothing was ever actually done. No good reason for this is apparent.

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272 Report on Macfarlane Trust communications April 2013 p13 WITN3372004

273 By roughly one third of respondents.

274 Katie Rendle Transcript 11 March 2021 p175 INQY1000108

275 Report on Macfarlane Trust communications April 2013 pp36-37 WITN3372004

276 Katie Rendle described this as an unfortunate decision. Katie Rendle Transcript 11 March 2021 p179 INQY1000108. She appears to have thought it was a way of kicking the issues into the long grass. Whether that was the intention or not, the effect was exactly that.

Jan Barlow’s own experience corroborated the views elicited by the survey undertaken by Katie Rendle. She learned from her first board meeting in January 2013 that there were real concerns about a lack of clarity concerning grants, a lack of transparency about what could be applied for and how decisions were taken, a need for a full-scale reorganisation of the process, complaints about an unhelpful tone being adopted in many communications, and in particular the length of time it took for applications to be approved. She said: *“In some cases grants that went through NSSC were taking months and months and months to get approval because the committee would ask for certain amounts of information and when they got that then they’d ask for additional information and, kind of, you know, this could go on for a long time”*.<sup>277</sup>

When she came into post, applicants for many grants had to show *“exceptional circumstances”* if they were to succeed – but quite what constituted *“exceptional circumstances”* remained unclear, even to those administering the system.

Concerns reached the ears of MPs. Within two years the All-Party Parliamentary Group (“APPG”) reported on current provision for support. Its report examined the operations of all the Alliance House Organisations. Among its chief findings were that only just over half of the applicants for grant support were positive about their experience of contacting their trust; that their understanding of how trusts operated in offering additional support<sup>278</sup> was low; that most applicants for additional support had little knowledge of how an organisation made decisions, or what processes were involved, and that nearly two thirds found it difficult to understand the rules and procedures involved. Levels of satisfaction with the overall support provided were low: less than a third were satisfied that the organisations being considered provided support efficiently, and less than one fifth were satisfied that it was given fairly. The report highlighted the fact that although applications to the Macfarlane Trust for support by way of a single grant were more likely to be successful statistically, when compared with applications to the Caxton Foundation or Eileen Trust, applicants to the Eileen Trust were most likely to describe their experience positively (almost 9 out of 10 did so). More than half described their experience of contacting Caxton positively (57%). By contrast, the figure for the Macfarlane Trust was 44%.<sup>279</sup>

## Causes of the poor relationships between beneficiaries and the Macfarlane Trust

It is clear from the above account that relationships between the Macfarlane Trust and its beneficiaries were never easy. The weaknesses in the way in which the Trust was first established saw to that, and a continuing insecurity of funding helped to perpetuate it. However, the attitudes adopted and shortcomings in the way in which the Trust operated

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277 Jan Barlow Transcript 3 March 2021 pp23-27 INQY1000103

278 ie support beyond the making of regular monthly payments.

279 All-Party Parliamentary Group on Haemophilia and Contaminated Blood Inquiry into the current support for those affected by the contaminated blood scandal in the UK January 2015 pp107-108, p120 RLIT0000031

accentuated these problems. They grew worse. Many of the specific practices which contributed to the problems have already been identified. However, those problems were further increased by a shift in the demographic of the beneficiary cohort. Life expectancy improved substantially. This resulted in a cohort whose needs had increased with age and the after-effects of treatment, but whose ability to meet those needs had reduced: employment was particularly difficult with a history of repeated illness and HIV infection, a lack of incentive at an early age to take full advantage of educational opportunities, or ill-health preventing them doing so, and the need for frequent and unpredictable visits to hospital.

A central problem concerned the way funds were allocated. What upset many – indeed, it seems, most – beneficiaries was the lack of anything more than the rudimentary information they were being given. They knew they could apply for a grant, but did not have clarity about how to do it, what it could be for, how much would be allowed, when they should apply, how long it would take, and what criteria would be applied in determining it.

This was then coupled for those who did apply with a process which:

- (a) was time-taking and bureaucratic
- (b) required (usually) more than one quote
- (c) had to have support in most cases from their treating clinician
- (d) might involve giving details of income and expenditure (despite the fact that many of the details had already been provided)
- (e) might involve being visited at home or photographs being taken of the quality of their environment in order to show it was sufficiently poor
- (f) required it to be shown that other sources of support and funding were not available

Both the lack of information from the Trust and the characteristics of the process described above were unfair to, and caused unnecessary distress and anxiety to, applicants; this was obviously not the right way to treat people who had already been profoundly harmed by the state.

Many applicants were aware at the same time that the Trust had substantial reserves which it was not prepared to dip into to meet what to them were pressing needs.<sup>280</sup>

Four particularly troubling aspects beyond even those relating to the allocation of funds also shaped the patterns which ultimately provoked the disappointed responses of beneficiaries.

First, the Macfarlane Trust lacked a clear idea of what its relations with the Government should be. Initially, four of its trustees were appointed by the Government. Its only source of funding was the Government and it determinedly set its face against fundraising.<sup>281</sup> It did

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280 A description of the allocation of funds and the shortcomings of the Trust in the way this was done are explored in greater detail below – this part of the chapter is intended to outline what caused dissatisfaction amongst beneficiaries of the Trust.

281 Peter Stevens Transcript 23 February 2021 pp40-41 INQY1000098

not have sufficient staff to pursue this effectively. But the principal reason it did not fundraise was of its own choosing. It was thought that to the extent that the Trust succeeded in raising funds it would cease to have equivalent funds allocated by the Government. Its efforts would thus be spending staff resources to favour the Government, not the beneficiaries.

Second, though the Trust was created as an institution independent of the Government, it felt itself in a subordinate role. Thus, for instance, Peter Stevens, chair of the trustees from 2000 to 2007, sought advice from the Government as to the meaning of the Trust deed, even though it was an independent Trust (and thus the view of the Government as to the meaning of the Trust deed was legally irrelevant). He did so because the Trust was set up at the instigation of the Government, and the Department of Health was responsible to the Government for the running of the Trust. So it was (he explained) “*right that we should go to them and say ‘What did you actually mean?’*”<sup>282</sup> Looking to the Department of Health for definitive guidance had a long pedigree. At a meeting with Department of Health officials on 7 September 1989, the Reverend Tanner (the first chair of the Trust) was minuted as saying that the meeting had been sought because the Trust was looking for an “*assurance*” that the policies and practices adopted were “*rightly fulfilling the objectives envisaged by the Government in setting up the Trust.*”<sup>283</sup> Another example, also from September 1989, is that a paper on allocation policy for widows (ie grants for widows)<sup>284</sup> spoke of such grants as the area of expenditure “*most vulnerable to criticism by our paymasters as encroaching on the grounds of compensation, and thus could in time affect any decision to allocate any further funds.*”<sup>285</sup> The view of the trustees was not that widows and dependants were secondary, or deserving of less consideration, but that they thought the Government would see matters that way.<sup>286</sup> It is right to note that, also in September 1989, an internal Department of Health briefing referred to the Department of Health strictly observing the independent status of the Macfarlane Trust, but then noted that the Minister of State for Health had requested two-monthly reports on the Trust’s activities.<sup>287</sup>

The same uncertainties persisted over time – ten years later, a strategic review conducted for the Trust suggested that the Department of Health provide policy guidance and priorities given increased life expectancy and needs.<sup>288</sup> Yet this, quintessentially, was the proper function of the trustee board and not a direct concern of the Department of Health. The

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282 Peter Stevens Transcript 23 February 2021 p11 INQY1000098

283 Minutes of Macfarlane Trust and Department of Health meeting 7 September 1989 p2 MACF0000076\_026

284 Not authored by Peter Stevens.

285 Annex H to Minutes of Macfarlane Trust Trustees meeting 28 September 1989 p25 MACF0000002\_018

286 Peter Stevens Transcript 23 February 2021 pp66-68 INQY1000098. If regard had been had to the Trust deed itself, this view is irrational. As already pointed out widows and dependants were expressly to benefit from the Trust if they were in need. The Government had played a hand in the drafting of the Trust deed, even if once entered into the Government could no longer have any authoritative view as to its interpretation: it is thus difficult to see why having agreed that widows should be beneficiaries, the Government should now consider that they should be excluded from significant benefit.

287 Department of Health briefing for meeting with Macfarlane Trust 7 September 1989 p1 DHSC0003318\_006

288 Final Report on the Macfarlane Trust Strategic Review January 1999 p5 MACF0000045\_019

view which the trustees took of their relationship with the Department of Health is indicated in a letter in relation to funding the strategic review. Reverend Tanner, as chair, had asked the Department of Health to provide funding to complete the review.<sup>289</sup> Having been told in reply that all relevant grant funds were fully committed, but “*If you are unable to attract funding from any other source*” then the Trust could apply to the Government for funding in the next financial year,<sup>290</sup> Reverend Tanner responded that “*the Trustees are of the view that it would be wrong for the Trust, being the **creation and servant of the Government**, to be seeking commercial sponsorship, particularly when the confidentiality of our work is paramount.*”<sup>291</sup> The highlighted words are revealing, though the correspondence needs to be seen in context.

Third, the increasing needs of beneficiaries led to increasing demands upon the Trust, whose trustees felt themselves facing a rising tide of demand which could not be met without dipping into reserves, yet felt themselves equally unable to deplete the reserves because they would be sacrificing the Trust’s tomorrow for its then today. This shortage and chronic insecurity in respect of funds, and what was done about it (which has been criticised as insufficient) needs to be set out at some length.

Fourth, many beneficiaries thought that the trustees demonstrated an uncaring, dismissive and at times disdainful attitude towards them. This too deserves a full account, but I shall first turn to the insecurities of funding and failure to address need appropriately.

## **Insecurity of funding and failure sufficiently to meet need**

Some 18 months after operating under the Trust deed, it was becoming clear to the trustees that the expenditure was exceeding the income received from investments. The Trust had been set up to make distributions to support beneficiaries in need. Those needs were substantial. Accordingly, trustees raised the question of future funding from the Department of Health at a meeting which took place between the Macfarlane Trust and the Department on 7 September 1989. The Trust wanted to know from the Department of Health whether additional funding would ever be made available, or whether the initial £10 million was a one off payment, making the (obvious) point that without such additional funding “*future expenditure could be considerably inhibited.*” The minutes record the discussion as follows:

*“Following discussion, Mr. Heppell responded that Ministers would not want the Trustees to make more limited offers of help than they would otherwise consider reasonable, simply to conserve funds, and that each case would continue to be judged on its merits. However, the request for additional funds was a matter of timing, and he advised the Trust that the right time to approach Ministers about additional funding would be when the Trust funds were sufficient to*

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289 Letter from Reverend Tanner to Baroness Hayman 30 July 1998 p2 MACF0000174\_040

290 Letter from Baroness Hayman to Reverend Tanner 3 September 1998 p1 MACF0000174\_016

291 Emphasis added. Letter from Reverend Tanner to Baroness Hayman 22 September 1998 MACF0000174\_015

*meet commitment for only 2/3 years. An approach at the present time would be too early.”<sup>292</sup>*

By way of comment, this response avoided answering the question posed. Though the response was suggestive of a welcoming approach to requests for further funding, and Strachan Heppell, Deputy Secretary at the Department of Health, indicated that the work of the Trust was valuable, it fell short of a commitment to make further payments, and nor did it say how much might be provided. This left the Trust with uncertainty as to the appropriate level at which it should disburse its capital, and concerned to keep a reserve if it could to meet the considerable financial uncertainties of the future.

The annual expenditure of the Trust was around £2 million until 2000 (after which it rose to between £2.5 and £3 million). If it was to provide the level of support which the trustees thought appropriate, and which was needed to relieve the needs of the beneficiaries the Trust identified, it needed the assurance (and the fact) of continued and consistent financial support. Instead, government funding of the Macfarlane Trust in the 1990s to enable the continued support of beneficiaries was somewhat ad hoc. There was a further payment from the Government of £5 million after five years (30 March 1993), no further payment until March 1996 (then £2.5 million), another payment, also at the end of the financial year, two years later in March 1998 (£3 million) and then in January 2000 another single payment, this time of £2 million.<sup>293</sup> This section explores why that was.

The strategy adopted by the Department of Health on the question of the future funding of the Macfarlane Trust, which resulted in these uncertainties of funding, is shown in a briefing note prepared for Strachan Heppell in advance of a further meeting between Department of Health officials and the Macfarlane Trust on 5 March 1992: *“At 31 March 1991 the Trust had capital reserves of £7.25 million and gross expenditure of 2.3m a year, which offset by interest received on the fund means that the Trust is spending around £2 million a year from capital. By the end of 1992/3 funds will have reduced to around £3m”*.

The briefing continued:

*“It might be that £1/2m to £3/4m could be available for the original Macfarlane Trust. However this only represents 3-4 months spending and the Trust is not going to need an injection of this size in the immediate future. There is also the risk that an injection of this size in the immediate future could be misinterpreted either as a crisis injection or as a sign of waning government support. Our preferred*

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292 Minutes of Macfarlane Trust and Department of Health meeting 7 September 1989 p3 MACF0000076\_026

293 See Macfarlane Trust Annual Report for the period ending 31 March 1993 p5 MACF0000045\_026, Macfarlane Trust Annual Report and Accounts for the Year Ending 31 March 1996 p3 MACF0000045\_022, Macfarlane Trust Annual Report and Accounts for the Year Ending 31 March 1998 p7 MACF0000045\_020, Macfarlane Trust Annual Report and Accounts for the Year Ending 31 March 2000 p7 MACF0000045\_017



*course is to top them up periodically with sums to cover 2-3 years spending rather than spoon feed them annually.”<sup>294</sup>*

Strachan Heppell was told that William Waldegrave, the Secretary of State, had not approached the Treasury for money (a PES bid) for funding the Trust from Departmental funds for 1992/93, but had deferred it to the following year. The briefing note observed: *“It was agreed with Treasury when the bid was deferred that general assurances could be given about further Government funding to the Trust if they raised the matter. This year, we are repeating last year’s PES bid for £6 million to top up the existing funds to allow the Trust to spend at a rate of about £2.5m – £3.0m for 3 years. The Trust would be unable to ensure continuity of help without additional funds for 1993/4.”<sup>295</sup>*

In a letter to David Watters following that meeting, John Williams, the administrator of the Macfarlane Trust (and attendee at the meeting), set out his understanding of what had been said at that meeting:

*“We were given reassurance that:*

- a. The people with haemophilia and HIV would continue to be treated as a special case*
- b. The Government was happy with the work of the Trust and agreed that this was the best means of continued help with the special needs*
- c. The Trustees need not make arbitrary cuts in expenditure and might even make reasonable provision against inflation. Further funds would be provided in time to avoid any guillotine.*

*Unspoken but implied, was the view that the Government would prefer this not to become a public issue again right now and equally that they did not want to have to find the money right now. It was conceded that in a year’s time we shall have made further inroads into capital, and the ‘rescue’ price will be higher.”<sup>296</sup>*

It appears from this that although the Departmental strategy was not to provide any specific assurances to the Macfarlane Trust that there would be top up funds forthcoming, a general assurance that there would be further funds was nonetheless provided at the meeting. The level of funding was not assured.

It remains unclear why the Department of Health was reluctant to be open and transparent with the Macfarlane Trust from the outset as to their specific intentions to top up the Trust on a periodic basis. It may have been because ultimately spending decisions depended on

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294 Briefing for meeting between Macfarlane Trust and Department of Health 4 March 1992 p2 DHSC0003411\_007. The briefing indicated that a sum of £1 million was available if needed to make payments to “*HIV infected haemophiliacs*” (note that this does not refer to their families although they had very obviously been included as beneficiaries in the Trust deed), but some of that was to make payments under the litigation settlement (16 as yet unpaid).

295 Briefing for meeting between Macfarlane Trust and Department of Health 4 March 1992 p3 DHSC0003411\_007

296 Letter from John Williams to David Watters 6 March 1992 HSOC0013336. Emphasis in original.

the Treasury, which had to balance a range of commitments. If, however, its reticence was intended to discourage the Macfarlane Trust from being too generous in its disbursements of the funds then it was effective. By March 1993, assets had dropped to just over £4 million<sup>297</sup> and in that year there had been a decrease by 3.6% from the previous year on the sums paid out to beneficiaries.<sup>298</sup>

The payment of £5 million already mentioned was made by the Department of Health on 30 March 1993, and restored the capital funds of the Trust to a level close to that at which it had originally been.<sup>299</sup>

In March 1995 the Department was considering whether to provide a top up to the Macfarlane Trust in that financial year from the 1994/1995 underspend.<sup>300</sup> A decision was made to defer any top up to the following year, but the documentation illuminates two factors:

- First, it shows that the preference at that stage in the Department of Health was for the Macfarlane Trust to be funded via current year underspends rather than via PES bids.
- Secondly it shows that although the Department of Health was planning for future top ups, this information does not seem to have been shared with the Macfarlane Trust. Instead, rather general assurances were given.<sup>301</sup>

On 15 March 1996 a payment of £2.5 million was made by the Department of Health.<sup>302</sup> This was funded by in-year savings in the Departmental budget.<sup>303</sup>

The Inquiry heard evidence from Peter Stevens (and Ann Hithersay to a lesser extent) that during this period, the Macfarlane Trust was underfunded.<sup>304</sup> Charles Lister on the other hand gave evidence that during his tenure the Department of Health always found the money that the Macfarlane Trust asked for, and sometimes even a little more.<sup>305</sup>

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297 The level at which the Trust had always said it would need to start reducing spending.

298 Macfarlane Trust Annual Report for the period ending 31 March 1993 p7 MACF0000045\_026. The report noted that per capita the sum was an increase.

299 Macfarlane Trust Annual Report for the period ending 31 March 1993 p4, p7 MACF0000045\_026

300 Letter from T Kelly to Mr Scofield 16 March 1995 DHSC0003157\_007

301 See for example what was said to John Williams in a letter from Paul Pudlo of the Department of Health 28 June 1995 DHSC0003189\_012: *“On the point that you raised about future funding; as you know the Government has given its assurances in the past that it will keep under review the amounts available to the Trusts. I can confirm that continuing commitment and that we will be looking again at the position of funding for the trust early next year. You will appreciate that I cannot give any firm details at this time but I hope this provides the reassurance that you were seeking.”*

302 Letter from John Horam to Reverend Tanner 6 March 1996 DHSC0003202\_010, Macfarlane Trust Annual Accounts for year ending 31 March 1996 p3 MACF0000045\_022

303 Memos between Marguerite Wetherseed and Mr Guinness 4 March 1996 DHSC0004481\_010, Memo from Mr Guinness to Marguerite Wetherseed 28 February 1996 DHSC0004481\_011

304 See her oral evidence where she accepted that there were areas of unmet need but stated that each time the Trust went to the Department of Health for more monies, the requests were granted. Ann Hithersay Transcript 25 February 2021 pp40-44 INQY1000100. Peter Stevens Transcript 23 February 2021 p77 INQY1000098

305 Charles Lister Transcript 8 June 2022 pp80-89 INQY1000212. Charles Lister was head of Blood Policy from 1998-2003.

The two statements are not necessarily inconsistent. As Ann Hithersay made plain in her oral evidence, the Trust was very careful about what it asked for from the Department of Health in terms of funding, not wanting to appear “greedy”. She agreed that in fact the Trust only asked for what they thought they would receive.<sup>306</sup> An example of this is the fact that after ten years, the Trust was still only disbursing £2 million a year.<sup>307</sup> It does not seem to have occurred to the Trust that they could disburse (and so seek from the Department of Health) more; the fear of being left without funds was a significant driver of its policy in respect of payments.<sup>308</sup>

Further effort would be made under Peter Stevens’ chairmanship to obtain the additional funds that were so clearly necessary. The approach adopted regarded overt lobbying as potentially counterproductive.<sup>309</sup> The approach taken throughout was, rather, a “softly, softly” one. It aimed to have the Government understand the problems of beneficiaries rather than an approach which “fired up” the press.<sup>310</sup>

He therefore requested a top-up payment of £4 million for 2001-02 from the Government to meet needs which had been identified in a strategic review of 1999.<sup>311</sup> This review showed that 70% of the beneficiaries who responded to the review questionnaire were largely dependent on state benefits, augmented by Macfarlane Trust funding, to meet their financial needs. This was well over twice the national average of people living at or below the poverty line.<sup>312</sup> It revealed that poverty and despair about money were common; that many were bogged down by debt; that few had any leeway to meet unexpected bills. It recommended that the Trust should approach the Department of Health to secure an assurance of continued funding, and that this should be at a level sufficient to meet registrants’ needs. However, Peter Stevens told the Inquiry that the response of the Department of Health was to “kick it into the long grass”.<sup>313</sup>

The way this happened, from government documents, shows the approach of the Department of Health. The case was made at a meeting on 18 April 2000. The briefing note produced by officials in advance of that meeting stated that the Trust wished to discuss an increase in funding to fund their programme of disbursements from £2 million per annum 1999/2000

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306 Ann Hithersay Transcript 25 February 2021 p59 INQY1000100

307 Peter Stevens told the Inquiry that he was very surprised by this when he returned as a trustee to the Macfarlane Trust in 1999. Peter Stevens Transcript 23 February 2021 pp86-88 INQY1000098

308 The documents suggest that it was not until the beginning of 2000 that the trustees decided to increase annual disbursements to £2.5 million and to approach the Department of Health for additional funds for this purpose. See for example Minutes of Partnership Group meeting 28 February 2000 p4 MACF0000088\_026 and Agenda for meeting with Macfarlane Trust 18 April 2000 p1 DHSC0003264\_004

309 Peter Stevens Transcript 23 February 2021 p127 INQY1000098. Patrick Spellman, a trustee who had high-level experience of the Civil Service, advised to this effect.

310 Peter Stevens Transcript 23 February 2021 p124 INQY1000098. This approach was consistent with the feeling mentioned above in the text that the trustees were subordinate to the Government and to an extent beholden to it.

311 Agenda for meeting with Macfarlane Trust 18 April 2000 p3 DHSC0003264\_004

312 Final Report on the Macfarlane Trust Strategic Review January 1999 pp14-15 MACF0000045\_019

313 Peter Stevens Transcript 23 February 2021 p99 INQY1000098

to £2.5 million per annum the following year, rising to £3 million by 2005/2006. The note records the following: *“It is hard to resist the Trust’s request for additional funding to meet the needs of registrants when the Trust is acting within the terms of its remit as laid down by the Trust Deed.”*

Despite this apparent acceptance of the case being put forward by the Trust for increased funding, the note continued: *“However, before additional funds are committed (assuming the money can be found in 2001/2002) we recommend that the Department commissions an independent review of the Trust’s activities.”*<sup>314</sup>

A further review, paid for by the Department of Health, was therefore commissioned in 2001.<sup>315</sup> This recognised that the financial assistance provided by the Trust had increased above predicted levels, causing significant pressures on its finances. On the assumption that income from the Department of Health remained a constant at £2.5 million per year and returns on investments remained constant at 4% per annum, then if the total paid out to registrants continued to increase by 12% per year as it had done for the four years preceding the review, the assessment was that the Trust would run out of funds by 2006.

The review concluded that the current financial management arrangements failed to provide adequate levels of information on which to base strategic decision-making. This was in part a result of the lack of internal management resources. It recommended that a business case should be put to the Department of Health for a review of current staffing arrangements and the benefits that would provide. It also recommended that receipts were requested from all who received funds, and that it was made clear that where receipts were not provided this would be taken into account in considering further claims on the Trust.

This “Macfarlane Review” was essentially into the financial administration of the Trust, rather than the policies which it had adopted for the giving of grants, although an implication was that the breadth of grant-making should be restricted if the Trust was to ensure its longer-term survival.

### **Ad hoc nature of the funding up to 2002**

The financial history of the first 14 years of operation of the Macfarlane Trust is one of a fear, on the part of the Trust, that funds might in future prove inadequate to meet the very real needs with which they had to deal day by day. General reassurances were given that money might be found if really necessary, but no particular level of income was assured on a continuing basis. Nor had sums been given annually. Funding was ad hoc. The responsibility for these uncertainties of funding were placed in the evidence of Peter Stevens at the door of the Department of Health.<sup>316</sup> For his part, Charles Lister testified that prior to 2002 the problem lay with the approach of the Macfarlane Trust. According to him the system in

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314 Agenda for meeting with Macfarlane Trust 18 April 2000 pp3-4 DHSC0003264\_004

315 Department of Health Macfarlane Trust MACF0000006\_010. It was conducted by Kat Macfarlane of the health services corporate management, and has been termed the “Macfarlane Review”.

316 Peter Stevens Transcript 23 February 2021 p77 INQY1000098

place for funding the Trust was, from the Department of Health’s point of view, reactive. The Department of Health therefore relied upon requests for more funds coming from the Macfarlane Trust, albeit it was the convention that no such request should be made until the reserves had dropped to about £4 million.<sup>317</sup> According to Charles Lister, these requests were made by the Macfarlane Trust for funds within the financial year when that occurred. Such requests did not fit with the way in which the Department of Health’s budget was set (in advance, usually on a three year cycle for budgets within the spending review, and annually for budgets outside that system). This led, in his words, to his team “*having to have an end of year negotiation with DH Finance to say ‘Can you find 2 million’, or whatever it was, ‘for us to give to the Macfarlane Trust out of end of year underspend’*.”<sup>318</sup>

Both witnesses were (rightly) of the view that this was not a satisfactory way of funding any organisation.

It helps in resolving the question of why general funding (as distinct from administrative costs) was delivered in the sporadic manner it was, to note, first, that in 1995 the Department of Health expressed a preference to funding the Macfarlane Trust out of that year’s underspend rather than by PES bids. This decision meant that funding decisions were made somewhat last minute as a result of in-year applications, for it was not until the end of a year that underspends became apparent. Second, there is evidence of the Macfarlane Trust informing the Department of Health of the funding they would need in forthcoming years. For example there is correspondence from October 1999 in which the Macfarlane Trust sought funds from the Department not just for that financial year, but also for the financial year 2002/2003.<sup>319</sup> These facts are persuasive that the ad hoc nature of funding – which both Charles Lister and Peter Stevens thought was an unsatisfactory way of funding any body such as the Macfarlane Trust – cannot be laid at the door of the Macfarlane Trust. It was more likely to be the Department of Health’s responsibility.<sup>320</sup>

The impact of these funding uncertainties before 2003 caused problems for the trustees of the Macfarlane Trust in that it “*coloured*”<sup>321</sup> their ability to respond to requests made to the Trust and hampered any proper long term planning as to how best to meet the needs of beneficiaries.

### Funding 2003 and beyond

A bid for the Trust’s funding was included by Charles Lister within the bids for the Spending Review (covering the 2003-2005 period). As a result of this, the Trust was allocated a budget for three years within the Spending Review, with the first payment of £3 million being paid in

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317 Charles Lister Transcript 8 June 2022 p81 INQY1000212, Written Statement of Charles Lister para 5.121 WITN4505002

318 Charles Lister Transcript 8 June 2022 p82 INQY1000212

319 Letter from Ann Hithersay to Charles Lister 28 October 1999 DHSC0003209\_009

320 There were no doubt pressures on public funding throughout this period, such that ministers had difficult decisions to make regarding the allocation of funds. That is not, however, a sufficient answer.

321 Peter Stevens Transcript 23 February 2021 p85 INQY1000098

May 2003).<sup>322</sup> Thus it was not until 14 years into its existence that the Macfarlane Trust had some level of financial security from the Department of Health. Nonetheless, the needs of the beneficiaries were still far from satisfied by these sums.

Whereas the review in 2001 had focused on the financial management of the Trust, in 2003 there was a further review – “the Long-Term Review” conducted by Hilary Barnard. This was seen as a means to establish new priorities for the Trust and to look at different ways to use limited funds: its commissioning reflected that the trustees wanted to establish “a firm basis on which the Department [of Health] would be unable to resist [their] pleas for more money.”<sup>323</sup>

This long-term review was entitled “*A Full Life – Not Just Existence*”. It concluded that: “*The Trust is not and should not be solely a grant giving Trust but has equal and integral roles in providing non financial help to the registrants, infected intimates, widows and dependents [sic]*” and that it should aim “*to support lives, not just existence.*” It said: “*It is rare that the Trust has much to do with parents these days but some remain as significant carers who the Trust should keep close contact with. Longer term survival of sick registrants carries with it far greater demands and impact on the lives of their supporters ... Addressing the needs of widows and dependents [sic] is a significant and extended claim on the resources of the Trust and its funder, the Government.*”<sup>324</sup>

Though Hilary Barnard recognised that the Trust had never been a public campaigning body, it did “*have an important role to inform, influence and persuade decision makers, drawing on the information and knowledge gained ... about the community of need it serves.*”<sup>325</sup>

Although the report had suggested approaching the Government in the immediate future, this did not happen. The reason it was not pursued straight away was because the focus of Peter Stevens’ work, and that of Martin Harvey, had now (August 2003) shifted to setting up the Skipton Fund. It had just been announced that there would be such a fund. They were asked to assist. Peter Stevens thought that Martin Harvey and he could not do both jobs (Skipton and Macfarlane) at the same time, given the resources available, and accepted in evidence that as a result the important work of presenting a case to the Government for increased funding for the Macfarlane Trust was not followed through as promptly and efficiently as it should have been. Nor, for that matter, did he ask the Government for more staffing resources.<sup>326</sup> Nor did he suggest that he had too much to do in relation to the Macfarlane Trust to spend further unremunerated time on setting up a further body. These failures have some mitigation in that it was the Government which invited his co-operation

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322 MacFarlane Trust Annual Report for the year ending 31 March 2004 p7 MACF0000045\_013

323 Peter Stevens Transcript 23 February 2021 p108 INQY1000098

324 The Macfarlane Trust Long Term Review *A Full Life – Not Just Existence* October 2003 para 1.5, para 5.4 MACF0000172\_001

325 The Macfarlane Trust Long Term Review *A Full Life – Not Just Existence* October 2003 para 5.5 MACF0000172\_001

326 Peter Stevens Transcript 23 February 2021 pp112-116 INQY1000098

in setting up Skipton.<sup>327</sup> He was fearful that although most of the Macfarlane beneficiaries were co-infected with Hepatitis C, and payments from Skipton could go some way towards meeting their unmet needs, there was a risk that they would be considered ineligible. He said as much when giving evidence to the Archer Inquiry.<sup>328</sup>

The delayed business case was eventually put to the Government in late November 2005. Peter Stevens commented that the Trust had started out with £10 million and had been expected to last five to seven years. It was “*topped up, topped up, topped up, at some stage you actually had to say no, we started in the wrong place, we’ve got to start again at a much higher level.*” He asked for an increase in funding to £7 million per year, supported by the business case.<sup>329</sup>

The business case did not reach the relevant junior minister’s office until the middle of June 2006.<sup>330</sup>

There had been a delay of several months. During this period – though not until May and June – there was discussion about the funding that might be available to the Trust. Initially officials were considering providing a five year settlement of £9 million to the Trust, to be reviewed in 2010, with no change to the recurrent funding level of £3m per year.<sup>331</sup> By 8 June 2006 this figure had reduced to additional funding split between the Macfarlane and Eileen Trusts of £400,000.<sup>332</sup> Caroline Flint was unable in her oral evidence to throw any light on what had happened to reduce the funding available so significantly.<sup>333</sup> Certainly by the time the information came to her, she was told that nothing more than £400,000 was available. The submission that went up to her stated:

*“As you know, DH has faced acute pressure on NHS funds and (as a consequence) on the raft of central budgets from which MFT and ET are funded. Major ALBs are being required to make challenging cuts in expenditure, to the point of ‘thinking the unthinkable’ about service reductions. The upshot of the prolonged review is, quite simply, that an extra £4m for MFT and £137k for the ET is not available. The most that could be found, within the budgets now available to us, might allow*

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327 The Government appeared to him to have no other plan at that time. It is open to the comment that the Government may have trespassed upon his willing nature.

328 *“one of the reasons why the MacFarlane Trust chose to get involved in the first place is that the indications from the original announcement and subsequent elaboration of that were that members of the – – registrants of the MacFarlane Trust would not be eligible because the government felt that they had already received sufficient, and we took the view that that gave us a little bit of leverage to ensure that our people, wearing my MacFarlane hat, as it was then, did participate as well.”* Peter Stevens Archer Inquiry Transcript 4 June 2007 p14 ARCH0000005

329 Peter Stevens Transcript 23 February 2021 pp116-123 INQY1000098

330 The Parliamentary Under-Secretary for Health was at that time Caroline Flint. Written Statement of Caroline Flint paras 2.97-2.197 WITN5427001

331 Email from Brian Bradley to Jonathan Stopes-Roe and Gerard Hetherington 17 May 2006 p1 DHSC5011528, Memo from Brian Bradley May 2006 p3 DHSC5011529

332 Email chain between Brian Bradley, Gerard Hetherington and Jonathan Stopes Roe 8 June 2006 p1 DHSC6294575, Memo from Brian Bradley June 2006 DHSC6340821

333 Caroline Flint Transcript 16 September 2022 pp20-29 INQY1000241

*for growth of around 10%, or £400k across both Trusts. Officials have so far informally advised the Trust to plan on the basis of ‘flat cash’ funding for 2006/7.”*<sup>334</sup>

While it is clear that what was being offered was what was said to be affordable, the advice to Caroline Flint also attempted some analysis of the business case:

*“Using MFT’s own figures, the average annual level of benefits payment per registrant since 2001 is 70% greater in real terms than the equivalent figure for the previous 12-year period. The historical data (see Annex B) indicates that the average annual payment to each registrant was relatively constant at around £3,500 from 1989 to 2001, when there was a step increase to an average of around £6,000. **This supports the view that the Trusts have already secured much, if not all, of the increase in the rate of annual benefit needed by registrants. Blood policy colleagues have commented that they do not consider any increase in overall funding is justified.**”*<sup>335</sup>

By way of comment, the only basis apparent from the wording for thinking that no increase was “justified” is what is seen as a high level of payment in the past. It is unclear how officials could have come to this view after reading the business case, supported as it was by the Barnard review. The review clearly set out that the beneficiaries of the Macfarlane Trust had significant unmet needs, ranging from the need for housing repairs (arising because at least half of the registrants were owner occupiers so unable to go elsewhere to meet such costs, and in poor health so unable to carry repairs out themselves), to the urgent need to reduce or eliminate debts, as well as meet the additional costs of living with a bleeding disorder and the infection of HIV and all that came with them.

Then, on 22 July 2006 the Minister of State for Public Health, Caroline Flint, sent a memo to the Secretary of State, Patricia Hewitt.<sup>336</sup> She described how the “*present pressure on central budgets*” did not provide for an increase to £7 million, that she was not convinced that the case was strong enough, nor that some of the expenses mentioned in a meeting with Trust representatives and in the business case were appropriate to the Trust. She added that “*officials have, all along, informally briefed the Trusts that additional funding would be unlikely. In response, the Trusts’ Chief Executive has, equally informally, indicated to officials that they understood this, at least at the senior level.*”<sup>337</sup> The purpose of the memo was to obtain the views of the Secretary of State as the issue was emotive. It is plain that she did not disagree.<sup>338</sup>

334 Memo from Brian Bradley on Macfarlane and Eileen trusts funding 14 June 2006 p2 DHSC5026530

335 Emphasis added. Memo from Brian Bradley on Macfarlane and Eileen trusts funding 14 June 2006 p2 DHSC5026530

336 Memo from Caroline Flint to Patricia Hewitt 22 July 2006 DHSC0006259\_044

337 Peter Stevens said in evidence that he understood the position of the Government, not (as the memo might be taken to imply) that he sympathised with it, even if he had to advance the case he did out of duty. Martin Harvey, the CEO, is not available to comment on what he meant. Memo from Caroline Flint to Patricia Hewitt 22 July 2006 p2 DHSC0006259\_044

338 Written Statement of Caroline Flint paras 2.164-2.170 WITN5427001



On 28 July Caroline Flint wrote to Peter Stevens. She said:

*“I have considered carefully all the points that were made at our meeting. I have also looked at the wider picture, including trends in numbers of registrants, and the level of benefits available from the Trusts’ funds. I am satisfied that an increase of £400,000, approximately 11%, to the Trusts’ funding will maintain an appropriate level of support to their remaining registrants and is within the current level of Government funding that is available. This will bring the funding each year to £3.754 million for the Macfarlane Trust, and £177,000 for the Eileen Trust (assuming a 90:10 split on the current ratio of their size). Both these figures include provision for administration costs.”*<sup>339</sup>

This decision, and the way it was expressed, left Peter Stevens seething. He described it as “*absolutely outrageous*”, “*typical civil servants’ smokes and mirrors*.” He was so rude to the senior civil servant involved that he had to apologise. He told the Inquiry that he had expressed himself to Caroline Flint “*in terms she wouldn’t normally expect to hear outside the Houses of Parliament*”, and the next month had proposed to the trustees that they should tell the Minister that they were prepared to resign. They rejected this call to arms.<sup>340</sup>

What particularly got under his skin was the Minister describing the increase as being of 11% when it was at best hardly an increase at all, because the figures now included provision for the costs of administration which had hitherto been paid separately by way of a Section 64 grant, which was the mechanism for providing grants to voluntary organisations.<sup>341</sup> Despite his outrage, to the point that he proposed resignation, he maintained a view that a campaign in the media would have changed nothing, and was likely to be counterproductive. The media, in his view, would pick holes in it, and his general attitude was to ask “*how it would look to the readers of the Daily Mail*”. Though he had the view, for these reasons, that a media campaign would not be productive, he never approached the media nor sought advice to see if that was indeed the case.<sup>342</sup>

339 Letter from Caroline Flint to Peter Stevens 28 July 2008 HSOC0005411

340 Peter Stevens Transcript 23 February 2021 pp133-134, p135, p140, pp145-147 INQY1000098

341 Peter Stevens Transcript 23 February 2021 p134, p141 INQY1000098. He was making a valid point: in evidence Caroline Flint accepted that the letter was not as clear as it might (her first expression) or should (her later choice of word) have been. Caroline Flint Transcript 16 September 2022 pp33-34 INQY1000241. The letter described the increase as “*maintain [sic] an appropriate level of support to their remaining registrants*”. Letter from Caroline Flint to Peter Stevens 28 July 2008 HSOC0005411. She accepted that “*appropriate*” was not the right word to use. Caroline Flint Transcript 16 September 2022 p35 INQY1000241. The evidence is also that in mid June 2006 she had suggested reducing running costs to provide more money for support, though this is not explicit in the letter to Peter Stevens: Note from Jack Buchan to Caroline Flint 15 June 2006 DHSC0041159\_237

342 Peter Stevens Transcript 23 February 2021 p32, pp150-151 INQY1000098. There is evidence that Peter Stevens did press the case in private discussion with civil servants: Sue Phipps, for example, a fellow trustee of the Eileen Trust, said in her statement that he “*never stopped working to try and protect the rights of the registrants and their access to the support that he had done so much to ensure was available to them*.” Written Statement of Sue Phipps para 112 WITN4682001. A reasonable inference from this is that he took a similar approach when chair of the Macfarlane Trust. In a similar vein, Charles Gore said with regards to the Caxton Foundation that he thought Peter Stevens “*made every effort to ensure the Caxton Foundation was a well-run organisation*.” Written Statement of Charles Gore para 35 WITN4530001. Peter Stevens himself talked of the discussions he had “*time and time again*” with the Department of Health: “*as long as the Macfarlane Trust was involved and*

By September 2007 there was somewhat of an impasse between the Trust and the Department of Health regarding funding. The Trust, now under the chairmanship of Christopher FitzGerald, met the Department of Health on 4 September 2007. The minutes record that the board of trustees “are unable to satisfactorily fulfil their objectives set out in the Trust Deed to ‘relieve the need of its beneficiaries’ and the Department are not in a position to increase the annual level of funding it grants to the Trust”.<sup>343</sup> The incoming Minister of State for Public Health, Dawn Primarolo, was informed in a letter from Christopher FitzGerald that the trustees considered the level of funding to be inadequate.<sup>344</sup>

Christopher FitzGerald did make a powerful case in public. He gave evidence, openly, to the Archer Inquiry in which he did not shrink from criticising the Government. He contrasted the “commitment” of government with the delivery of the funding which appeared actually to have been committed; he said that the trustees might be entitled to see the Government as having set up the Trusts so that the plight of beneficiaries would be moved from being a political problem to making it an administrative one, and called for a renewal of political commitment to the objectives. He added: “I would simply wish to reiterate that it is simply unacceptable on any basis, whether you call it moral, legal or whatever – – it is simply unacceptable that the funding the consequences of the greatest catastrophe in the history of the NHS should be constrained by the current financial difficulties or incompetencies in the NHS.” He was clear that the trustees:

*“are charged with a duty under our trust deed to relieve the needs of our beneficiaries. We cannot perform that duty unless adequate financing is provided, and to do that ... the politicians have got to recognise the fundamental change that has taken place in the needs of our beneficiaries, resulting from the fact that they are now expected to survive for a full lifespan, God willing, whereas, when the commitments were originally given, they were all expected to be dead within four to five years.”*<sup>345</sup>

Christopher FitzGerald wrote to the Government to complain that unless more money were given the Trust could not meet its objectives adequately and said the same to officials, though the Archer Inquiry was his main hope.<sup>346</sup> He did eventually achieve an assurance in 2008

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*I was involved with the Macfarlane Trust as a trustee, there was never enough money and the Department never, ever provided us with a sufficient assurance that money would be forthcoming ... Fortunately ... there was a senior civil servant then, Charles Lister ... who was able to institute a regular, annual, predictable annual, amount. It was never enough but at least we knew it was coming. But before then there was a period when we just didn’t – – we had no idea when we would see another sum, another penny, from the Department. So I’m sorry but I get really – – I get quite aerated by ... this sort of discussion we had time and time and time again with the Department and then with ministers ... I was almost speechless with anger at the minister involved at the time who said that she was satisfied the amount of money they were giving us was enough. I said she had no right to be satisfied, express satisfaction.”* Peter Stevens Transcript 23 February 2021 pp84-85 INQY1000098

343 Notes of meeting between Macfarlane Trust and Department of Health 4 September 2007 p2 MACF0000068\_075

344 Letter from Christopher FitzGerald to Dawn Primarolo 5 September 2007 pp1-2 MACF0000179\_013

345 Peter Stevens Archer Inquiry Transcript 4 June 2007 pp36-41 ARCH0000005

346 Letter from Christopher FitzGerald to Dawn Primarolo Minister for Public Health Protection 5 July 2007 MACF0000016\_039, Minutes of Macfarlane Trust and Department of Health meeting 28 October

that there would be annual funding indefinitely.<sup>347</sup> This allowed for a gradual reduction in the amount of the reserves since (given that assurance) they no longer had to be maintained as insurance against the uncertainty of funding in the future. Further, following the report of the Archer Inquiry the Government announced that in future there would be annual payments of £12,800 to each infected individual “*thus eliminating the need for them to make repeated detailed applications*” and, in effect, doubling their current average annual payments (these payments were made through a limited company called MFET Ltd, so that they were not dependent upon an assessment in each case of the precise charitable needs the payment was to meet).<sup>348</sup> It also agreed to increase the funding to Macfarlane Trust for dependants, whose applications for funding would continue to be dealt with by the trustees on a case by case basis.<sup>349</sup>

The Trust had initially been operating on the basis that it needed sufficient reserves to ensure that if no funding was forthcoming from the Department of Health, it had enough to keep going for a year. The uncertainty of funding in the early years is set out above. By the time Christopher FitzGerald was the chair, as he told the Inquiry in his oral evidence, the reserves policy had been reached following consultation with the Charity Commission. In 2007/2008 this figure equated to £4 million. The Trust’s annual report for 31 March 2007 explained the policy as follows:

*“the Trustees have concluded that the risks to the Trust’s ability to perform its functions through financial disbursements, both in terms of Government policy and of investment risk, remain such that their policy should continue to be to retain a reserves balance represented by its managed investment fund of around £4million [sic]. This is on the basis that £4million [sic] now represents roughly one year’s expenditure at the current rate of disbursement plus a provision for management costs. In coming to this conclusion the Trustees have regard, inter alia, to reference in the Charity Commission’s guidance on reserves to ‘the need to secure the Trust’s liability beyond the immediate future and to provide reliable services over the longer term’.”*<sup>350</sup>

By 31 March 2008 however the Department of Health had made enough of a commitment to give the Macfarlane Trust confidence that it would receive an annual allocation every year.<sup>351</sup> This commitment was made in a meeting at the beginning of 2008 attended by Christopher FitzGerald and Martin Harvey and is referred to in a document prepared for a Macfarlane Trust board meeting by Christopher FitzGerald in the following terms:

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1998 p1 MACF0000012\_131, Christopher FitzGerald Transcript 26 February 2021 p33 INQY1000101

347 Christopher FitzGerald Transcript 26 February 2021 pp34-35 INQY1000101

348 Government Response to Lord Archer’s Inquiry Report 20 May 2009 p8 HSOC0011282\_002. On 10 January 2011 Andrew Lansley, then Secretary of State for Health, announced that those co-infected with HIV and Hepatitis C stage 2 would receive £25,600 per annum (ie two payments of £12,800). Hansard Statement on Contaminated Blood 10 January 2011 pp1-2 WITN4688072

349 Government Response to Lord Archer’s Inquiry Report 20 May 2009 p8 HSOC0011282\_002

350 Macfarlane Trust Annual Financial Report for the Year Ending 31 March 2007 pp7-8 MACF0000045\_010

351 Macfarlane Trust Annual Financial Report for the Year Ending 31 March 2008 MACF0000045\_009

*“In response to our representations the Department confirmed both its intention ‘to continue funding the MFT on an annual basis’ and its commitment ‘to supporting the MFT and to make available a level of funding that is fair and reasonable, taking into all the circumstances into account’ ... These confirmations were then supplemented by the following: ‘The Department’s annual funding of the MFT is intended to enable the Trust to meet its obligations, and to contribute, as necessary, to the needs of the community of care as defined. This recognises the fact that many of the original reasons for creating the Trust and the subsequent statements of support are still pertinent. The Trust will therefore need to retain its position among the external bodies funded by the Department. The Trust must, however, recognise that future funding settlements will depend on other pressures and priorities that the Department is obliged to take into account at the time. The planned usage of the Trust’s reserves will complement the future funding view of the Department and will support the intention to maintain the current annual funding settlement.’”*<sup>352</sup>

The Macfarlane Trust board therefore accepted Christopher FitzGerald’s recommendation and decided at the board meeting of 14 July 2008 that the reserves policy only needed to be sufficient to cover six months of expenditure (ie both disbursements to beneficiaries and the cost of administration) plus 10% to allow a modest buffer against adverse market movements. While the annual expenditure figure at that point was £3.95 million, the board agreed to reduce the reserves down to £3 million so as to give sufficient cover in the event that a decision was made in the near future to increase regular payments or single grants.<sup>353</sup>

During 2011 the Trust settled on a reserve policy (as set out in its most recent annual report of 31 March 2011) of moving over time towards a level of having enough money to fund the Trust’s disbursement and running costs for a period of six months. This equated to £1 million.<sup>354</sup> By the end of 2011, the Department of Health focussed on the level of these reserves (which had been reported in the accounts in March 2011 as an investment portfolio of £4.1 million).<sup>355</sup> At a meeting on 8 December 2011, the Trust suggested to officials from the Department of Health that the reserves could be reduced within two years to a figure of £100-£200,000 if there was security as to continued funding. The Department responded that was in line with their views.<sup>356</sup>

However, the minutes of the meeting of 8 December 2011 also record that: *“Mrs Jecock said that MFT should recognise that the reserves might have to be used for a time to fund the Trust’s current commitments to Beneficiaries as financing was under tight review and DH*

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352 Memo on Reserves Policy for the Macfarlane Trustees Board meeting 14 July 2008 pp1-2 MACF0000051\_049

353 Memo on Reserves Policy for the Macfarlane Trustees Board meeting 14 July 2008 p3 MACF0000051\_049, Minutes of Macfarlane Trust Board meeting 14 July 2008 pp1-2 MACF0000018\_006

354 Macfarlane Trust Annual Financial Report for the Year Ending 31 March 2011 p10 MACF0000047\_017

355 Macfarlane Trust Annual Financial Report for the Year Ending 31 March 2011 p13 MACF0000047\_017

356 Meeting notes of Macfarlane Trust and Department of Health Annual Review meeting 8 December 2011 pp1-2 MACF0000061\_104

*Finance were limiting the pots of money to cover non-NHS programmes.*<sup>357</sup> The Department of Health’s view on the Trust’s level of reserves was therefore seriously out of step with the Trust’s assessment of what was appropriate – that is, unless appropriate security was given as to continued funding. Dr Rowena Jecock, Head of Blood Policy, was indicating that for the time being the Macfarlane Trust might receive little or nothing, but would have to use what it had in reserve instead.

The Trust plainly needed a reserve, particularly given the history. Christopher FitzGerald was justified when in oral evidence he said that *“we saw that it would be a grave risk, and indeed a dereliction of our duty, if we did not keep sufficient reserves to ensure that our beneficiaries were not just left to drop off the cliff.”*<sup>358</sup> Moreover, the Department of Health often seemed unable to provide the Macfarlane Trust with a decision on their annual allocation by the start of the financial year, and so the reserves were required to avoid serious cash flow problems.<sup>359</sup> Yet it was now being faced with a reduction in its annual allowance from government because of holding a reserve, which the previous behaviour of the Department of Health had effectively required it to do. Dr Rowena Jecock in her oral evidence accepted that the level of the Trust reserves was taken into account when setting the annual allocation.<sup>360</sup>

When the chairmanship passed from Christopher FitzGerald to Roger Evans in 2012 the approach shifted again. Roger Evans’ attitude from the beginning was that he sought to ensure that what the Trust board did was in compliance with the wishes of the Department of Health as he understood them: it supplied the entire funding.<sup>361</sup> He raised matters with the Department of Health which the board thought might be of interest (such as the security of loans) and considered that to fundraise would be insensitive because the needs of the beneficiaries should be dealt with through central government.<sup>362</sup> He was reluctant for the Trust to campaign, since *“it was not our role, and probably would have been unhelpful to the Trust, to carry out high profile campaigning in a broader way”*, though he added that *“we*

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357 Meeting notes of Macfarlane Trust and Department of Health Annual Review meeting 8 December 2011 p2 MACF0000061\_104

358 Christopher FitzGerald Transcript 26 February 2021 p128 INQY1000101

359 Alasdair Murray, a trustee from March 2014 and the chair of the Trust from May 2016 until it was wound down told the Inquiry: *“in most financial years the government did not confirm our funding allocation until the new financial year had started, which created uncertainty about whether we would have the funding necessary to deliver the support we planned to provide to beneficiaries (and absent the reserves could have posed cash flow problems).”* Written Statement of Alasdair Murray para 42 WITN3076002. That this was the usual position is confirmed in a letter from Dr Ailsa Wight to Alasdair Murray on 17 March 2017 when she stated: *“We are not currently in a position to confirm the funding allocation for 2017/18 as we are waiting for the Departmental budgets to be finalised. As soon as we are told, we will issue the allocation letters. I appreciate this is difficult in terms of timing and planning; as you know we are rarely able to confirm the allocations in advance of the financial year.”* Emphasis added. Letter from Dr Ailsa Wight to Alasdair Murray 7 March 2017 p1 MACF0000061\_049

360 Dr Rowena Jecock Transcript 13 July 2022 pp145-146 INQY1000226

361 Roger Evans Transcript 4 March 2021 pp20-22, pp30-36, pp43-47 INQY1000104

362 At one point in his evidence he said: *“I think to go out and try and fund-raise, perhaps to substitute for what they should have been providing centrally, actually would have been insulting.”* Roger Evans Transcript 4 March 2021 p45 INQY1000104. This was his personal view: he did not ask any beneficiary about it nor, apparently, raise it with the trustees as a group.

*would have been very happy to have helped in it being undertaken but not for us to be in the forefront.*<sup>363</sup>

In 2012, the Trust came under repeated pressure to meet some of its expenses from its reserves. The Department of Health asked that a business case be submitted to support its funding request. It asked that the case should detail why the reserve had not been used for charitable purposes and what had changed to merit its distribution now. It asked specifically for an analysis of the data that had been obtained from a survey the Macfarlane Trust had commissioned, including an anonymised assessment of each beneficiary's current ability to pay for items, for a statement as to the standard of charitable need the Trust intended to apply to applications for grants from reserves, and to be told how the Trust planned to assess need.<sup>364</sup> Although Roger Evans accepted this was none of the Department of Health's business – which it was not: they were plainly over-reaching themselves – he did not say so to the Department of Health in writing. Nor did he say that he was unwilling to provide information on the three points just mentioned. He said he had nonetheless made these points orally – it was not his *“style to put immoderate words into a letter and email.”*<sup>365</sup>

Matters came swiftly to a head. There are differing accounts of what happened when it became clear that funding for 2013-14 was likely to remain inadequate. These accounts justify detailed consideration. They conflict to some extent, and are difficult to resolve. At a board meeting on 21 January 2013, Russell Mishcon, a trustee from 2006 to 2014, proposed that the trustees should write to the Department of Health threatening to resign as a board unless it provided better funding to meet the needs of the beneficiaries. He did so under “Any Other Business”. He produced a draft letter. The minutes (which would have been prepared by Jan Barlow as chief executive and agreed in draft by Roger Evans) recorded her as expressing the view that to send a letter to the Minister of the nature tabled, in advance of any decision being made, would not be constructive and would also remove any further room for negotiation if an unfavourable answer were received. The minuted record continues: *“Whilst several trustees were still in favour of sending the letter, others were*

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363 Roger Evans Transcript 4 March 2021 p46 INQY1000104. Pressed by Counsel on his view that the Trust should not take any leading role in campaigning, he said this was because: (a) he did not think it the role of the Trust to do so; (b) the Trust did not have the resources to do it; (c) he *“was somewhat nervous, if we were to be public in that sort of way, quite what the ongoing reaction would be from some of the beneficiaries, and it might be one which would actually be unhelpful to them as well as to the Macfarlane Trust.”* Roger Evans Transcript 4 March 2021 p55 INQY1000104. Roger Evans' predecessors as chair had taken a similar view in relation to fundraising and campaigning. It is only fair to note that when the criticism was put to Roger Evans under the Inquiry Rules 2006 he noted with justification that if the Trust were to fundraise effectively it would need to recruit the equivalent of two full-time employees, which would be a significant cost, and would need funding to be kick-started by having one or two wealthy donors prepared to contribute. It is also to be noted that a fellow trustee, Russell Mishcon, said in his evidence that to do so was not really the role of the Macfarlane Trust nor that *“having been set up by the Government, to administer funds to the registrant community, that it would be appropriate to ... fundraise.”* Russell Mishcon Transcript 9 March 2021 p10 INQY1000106

364 Email from Dr Ailsa Wight to Roger Evans 30 August 2012 p5 MACF0000060\_047

365 Roger Evans Transcript 4 March 2021 p141 INQY1000104. He described having a *“shouting match down the phone”* about this.

*either unsure or against, and two trustees were also not present. RE [Roger Evans] was not prepared to sign the letter.*<sup>366</sup> Thus far, there is little dispute about the facts.

However, Roger Evans' recollection now is that only three trustees (a minority of those present) were prepared to sign the letter.<sup>367</sup> This differs from an account he gave in his second written statement.<sup>368</sup> It does not accord with the minutes, in particular the use in those minutes of the word "*several*"; nor does it accord with the chair's decision to put the matter off with a view to further consideration at a later date. If a majority had been against the proposal, then given the style of Roger Evans' chairmanship<sup>369</sup> the matter would have

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366 Agenda and Minutes of Macfarlane Trust Board of Trustees meeting 21 January 2013 p10 MACF0000024\_002, Draft letter tabled at the Board of Trustees meeting 21 January 2013 WITN4474004

367 Roger Evans Transcript 4 March 2021 p64 INQY1000104

368 In his second written statement he states that two trustees "*thrust a letter addressed to DH/Minister [Department of Health], pressurising the CEO and I to sign stating, amongst other things, we should resign if additional funding was not forthcoming. I made it very clear that I had no intention of signing the letter or resigning. This was supported by all other board members.*" Written Statement of Roger Evans para 147 WITN3859002. This is an account of two, and two only, of the trustees being in favour of the letter. The difference between that and the three he mentioned in evidence casts some doubt on the reliability of his account.

369 He was adamant in his own views, to the extent that he tended to take disagreement personally, and quickly formed suspicions of the motives and behaviours of others which had little objectively to support them. Thus he considered that Alan Burgess, whom he considered as having the prime objective of undermining his position, was complicit, whereas the evidence of Alan Burgess and of Russell Mishcon (who alone was the author of the letter, and whose evidence on this is reliable) was that Alan Burgess had no part in it. Written Statement of Roger Evans para 9 WITN3859001, Russell Mishcon Transcript 9 March 2021 p31 INQY1000106, Written Statement of Alan Burgess para 18 WITN1122005. Roger Evans also said that Russell Mishcon "*took it upon himself to draft the letter*" (emphasis added) but added "*I am fairly sure, but not certain, that the remaining two [ie two of the three he now recalls supporting signing it] had assisted ... in drafting the letter.*" Written Statement of Roger Evans para 2 WITN3859003. There is no evidence to support such assistance, and it remains merely suspicion. He also said: "*I still suspect that the prime objective was to put me in an impossible position, rather than having any realistic expectation of it leading to increased funding.*" Written Statement of Roger Evans para 9 WITN3859001. When asked about the basis for this, he ascribed it to his view that "*from the time I was appointed as the chair, Russell and I had a strained relationship. Prior to that we worked well together on a number of things and for some reason the relationship changed. And he -- I had received -- sadly they are not available now with me anyway -- some rather threatening, hostile -- I don't mean threatening in a sort of legal way -- emails from him on my home account over a year or two and -- on various issues, and I thought -- and this was, in a sense, some sort of -- I saw it as possibly a sequel to that. And I think at best he was probably trying to embarrass me.*" Roger Evans Transcript 4 March 2021 pp103 INQY1000104. His view that Russell Mishcon was seeking primarily to embarrass and undermine him thus appears to have nothing objective to support it. A further illustration of his fears that others might be undermining him is his description of his suspicions of Jan Barlow's behaviour in 2016, namely that she was colluding with another in a way which lacked integrity to ensure that the Caxton Foundation took over the Macfarlane Trust: again, the Inquiry was given no objective basis for this. Written Statement of Roger Evans para 319 WITN3859002. He described the failure of Christopher Pond of the Caxton Foundation to turn up to meetings as sufficient basis for him to "*sense*" that he was more interested in his own advantage than the interests of Caxton, and speculated: "*He may well have been the architect of the covert attempted takeover by [the Caxton Foundation], leading to my resignation.*" Written Statement of Roger Evans para 318 WITN3859002. The Inquiry has uncovered no evidence of any attempted takeover, let alone that it was covert, and none that might imply that Christopher Pond was the "*architect*" of it. He also described how in his view unity and discretion amongst trustees were imperative: "*W1122's behaviour was the antithesis of these and unbecoming of a board member. Following complaints from fellow board members I had a conversation with him to that effect ... I wanted to strengthen board unity I, therefore, arranged to meet a trustee colleague of W1122 at the St. Ermin Hotel for a one to one talk about my concerns over our relationship and his behaviour as a board member. Without inform [sic] me, he brought two more trustees with them, one of whom was W1122. The invitee turned round the meeting to criticize my chairmanship, in an unpleasant and*

gone no further, and a decision to that effect would have been recorded. It does not fit with the recollection of those other than Roger Evans himself and Jan Barlow who were present from whom the Inquiry heard. Nor does it fit with an email shortly after the meeting from one of the trustees, Matt Gregory, to Katie Rendle, again a contemporaneous document, which says, in part “*I was thinking on my ... journey home that we had been forced to abandon a course of action that it was obvious that the vast majority of those present favoured.*”<sup>370</sup>

However, to the opposite effect are inferences that can be drawn from some later emails. The context for these are that Roger Evans sent an email to each trustee who had been at the meeting four days after Katie Rendle and Matt Gregory’s exchange, arguing against action that (as he saw it) might adversely affect negotiations with the Department of Health. Trustees responded to it. Russell Mishcon, in an email of 27 January (the next day), said in part “*this applies to three other trustees who have responded, making a total of four against the idea of sending a letter now. But we are a board of 9 trustees! And what if the two trustees who were not present at the Board Meeting had been in favour of sending a letter?*”<sup>371</sup> This therefore shows that as at that date, after Roger Evans’ round-robin email, a majority of those who had been at the meeting did not favour sending such a letter there and then. By then, according to Russell Mishcon, the letter had had some alterations to meet some of the concerns that had been expressed at the meeting about the tone of parts of it.

Reconciling these different expressions of view over a period in which some may have shifted is not easy – but I have concluded that no vote as such was taken on whether a letter in which the trustees en bloc threatened to resign should be sent, and that it was plain some would not have signed it. That seems clear beyond doubt. Others were unsure – that is recorded in the minutes, and is supported by Russell Mishcon’s recollection that a number of changes of wording were made in the light of some of the concerns. As to a revised letter, by 27 January four of those who had been at the meeting were probably not in favour of sending it immediately. The minutes did not record a vote, because one was not taken. They were vague (“*several*” is not a head count), probably because what was being encapsulated was an impression by the person taking the minutes of the general feeling in the meeting. On any view, this general feeling was mixed. Accordingly, the decision (probably of Roger Evans) was that further discussion would be deferred to a later date.

At the meeting, Roger Evans said that the Macfarlane Trust was an arm of the government “*whether we like it or not.*”<sup>372</sup> Though Roger Evans cannot recall saying this he accepts he may well have done, and since it was the focus of an email which Katie Rendle sent the next day to him, I consider he did. It represents his views: for instance, when asked by Jenni Richards KC about part of the email in which Katie Rendle had said: “*Our concerns*

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*disrespectful manner.*” Written Statement of Roger Evans paras 13-14 WITN3859001. The sense conveyed by this somewhat unusual behaviour on his part, and by his volunteering it in evidence, is that he regarded anyone who took a view different from his as either having improper motives, or behaving improperly, or both, and has little sense of how it may seem to objective observers.

370 Email chain between Kate Evans, Matt Gregory and Alan Burgess 22 January 2013 p1 WITN1122028

371 Email from Russell Mishcon to Roger Evans 27 January 2013 pp1-2 WITN1122029 (emphasis added).

372 Email chain between Kate Evans, Matt Gregory and Alan Burgess 22 January 2013 WITN1122028



*are not the government’s concerns, we do not exist to carry out their policies or to consider their overall financial position”, he replied: “Well, the reality was we may not like it but if our allocation is coming from the Department [of Health], we were in a position where they had some influence over us.”<sup>373</sup>*

As just mentioned, a few days after the meeting, Roger Evans sent an email to each trustee. In part of that he said:

*“Several of you have asked me what influence DH [Department of Health] has over the Macfarlane Trust. The answer is – a lot. The Government (through DH) set up MfT [Macfarlane Trust] in the first place and could close us down at any time if they so wished. DH appoints three of our nine Trustees and they are our sole source of funding. The relationship is bound up in a Trust Deed and an amended version was agreed unanimously by our Board a year ago. A DH appointed Trustee challenging DH in the proposed way would raise a number of questions within DH – about loyalty, for instance.”<sup>374</sup>*

The views expressed here are to be seen in the context, which is that of an email sent in an attempt to persuade trustees away from further supporting their threat of mass resignation. They are nonetheless troubling. As a matter of law, the Department of Health could not close down the Trust because as a charity it was an independent entity.<sup>375</sup> As a matter of principle, the duty of a trustee is to act in the best interests of the trust (which usually involves the best interests of the beneficiaries), and the interests of the appointing party are irrelevant.<sup>376</sup> they are trustees, and neither representatives nor delegates. Their loyalty is to the trust, and not to the party who may have appointed them. As a matter of comment, if the views expressed in his email were not Roger Evans’ true views, then to take this approach as a means to persuade trustees not to pursue collective resignation was an improper exercise of chairmanship. If they were his true views, they betray an attitude of resigned subservience to his personal perception of what the Government wished, and indicate a refusal to engage on the merits of any contrary opinion. The latter is more likely to be the case, and calls into question the wisdom of appointing a person with such views to become chair of a charity serving an ill and aggrieved beneficiary community.<sup>377</sup>

He accepted – rightly – that some at least among the beneficiary community would have thought that partly because of this attitude and approach, and the absence of robust

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373 Roger Evans Transcript 4 March 2021 pp66-70 INQY1000104. This conveys very much the same sentiment as the quotation in question.

374 Email from Roger Evans to trustees 26 January 2013 p3 WITN1122029

375 Roger Evans was prepared to accept that it might not be legally correct, but did not appreciate that at the time. Roger Evans Transcript 4 March 2021 p81 INQY1000104

376 This is axiomatic in being a trustee, and if he was not aware of it he should have been.

377 His view as given to the Inquiry was: *“there were ways of getting what you wanted from the Department of Health, or getting some of it, and the ministers and there were ways in which they would not respond.”* Roger Evans Transcript 4 March 2021 p87 INQY1000104. He did not articulate this in the email though it is probably the case that the trustees knew it was his viewpoint.

arguing for the needs of the beneficiaries, the Macfarlane Trust was too close to the Department of Health.<sup>378</sup>

His evidence about a decision taken in a board meeting of April 2013 to make an allocation from reserves below the level at which the programme of expenditure from reserves had been set in earlier documents contained the following exchange. When asked: “*Can you recall whether the reduced figure reflects a request or instruction from the Department of Health?*” the reply was: “*No, I can’t.*”<sup>379</sup> This is surprising. There should have been no doubt about the answer, in the context of the question. Though eight years had passed since April 2013 the matter was of some significance: any attempt by the Department of Health to request let alone instruct an independent board of trustees to act in any particular way should have been seen as memorable, and unforgettable.

The combined weight of this evidence makes it plain that the leadership of the Macfarlane Trust was less independent of its paymaster, and less observant of its obligation to serve the interests of its beneficiaries, than it should have been: and it suggests that there was in consequence a lack of vigour in pursuing better funding. There is also disturbing evidence of serious tensions between board members which went well beyond those normally to be expected in healthy debate, and were sometimes expressed in unnecessarily personal terms.

This is demonstrated by a remarkable letter of 12 February 2014 from two trustees,<sup>380</sup> who had retired at the end of January, each after several years of service. It was written to Jeremy Hunt in his capacity as Secretary of State for Health.<sup>381</sup> It made a highly unusual complaint to him about the behaviour of the chair, and complained also about Jan Barlow. As to Roger Evans, it said: “*Since his appointment, the chairman has failed to consult adequately, in our view, with the Board on matters of importance and upon strategy or to take trustees’ views into account. The minutes of Board meetings, which he oversees, are, we believe, ‘tweaked’ towards his own agenda and he does not suffer being challenged lightly.*” It complained that neither the chair nor the chief executive wished to rock the boat with the Department of Health. It suggested too that there had been a conflict of interest for the chief executive

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378 Roger Evans Transcript 4 March 2021 pp106-107 INQY1000104

379 Roger Evans Transcript 4 March 2021 p162 INQY1000104. It is difficult to place full reliance on what Roger Evans says in evidence where it lacks objective support: it must be approached with caution. One example is that in his evidence on 4 March 2021 there was a surprising exchange between Counsel and Roger Evans. He had suggested in evidence that one of the reasons why he had to go along with the Department of Health in its requests or demands for information, and some form of right or approval or sanction over the use of the reserves, was because the Macfarlane Trust needed actually to get the money (which constituted the reserves) from the Department of Health, which held them. When asked if the reserves were not money the Trust already held, he denied, at some length, that that was the case. This is wrong. It is and always was quite clear that it was wrong. What was most troubling therefore was his categorical assertion that it was correct. The context was his attempting to give a reasonable explanation for what appeared to be subservience to the Department of Health. He corrected his mistake the following morning, after Counsel had taken him to further documentation, said that he had realised overnight that he had been wrong, and apologised for what he described as a “*mental aberration*”. Roger Evans Transcript 5 March 2021 p8 INQY1000105. But this episode nonetheless demonstrates a recollection of fact which is unreliable, despite the persistence with which that fact may be expressed when first challenged.

380 Russell Mishcon and Elizabeth Boyd. It also claimed that two other trustees had resigned from their roles with the National Support Services Committee because of the behaviour of the chair.

381 Letter from Elizabeth Boyd and Russell Mishcon 12 February 2014 p1 WITN1122048

between her role for the Caxton Foundation and her role with the Macfarlane Trust.<sup>382</sup> They added that the chair had accused both of them of a “*witch hunt*”.

The letter was copied to the Parliamentary Under-Secretary of State for Public Health, Jane Ellison, and to the Charity Commission. Roger Evans did not accept what was said. His view was that he did listen to, and took proper note of, what other trustees were saying and wanting, though he did not always agree. He did, however, comment that the board was “*a much more relaxed Board than it had been before*” after Elizabeth Boyd and Russell Mishcon left, and that he had “*very little doubt that I was being quite firm on certain issues.*”<sup>383</sup>

In summary, the Trust neither functioned well in its relations with its beneficiaries, nor (at least after 2012) did it function well internally at management level.

### Funding issues after 2014

Following the exchange in 2011, and the pressure placed on the Trust in 2012 to use its reserves to part fund its annual allocation, the extent to which those reserves were exhausted began to affect, even more, the Trust’s ability to meet the needs of its beneficiaries. By November 2014 the annual shortfall experienced by the Trust between the Department of Health’s allocation and their grant giving programme was £800,000. In a letter from Roger Evans to the Department of Health, the Trust made the following points:

*“As we made you aware through last year’s business case, for some time we have only been able to run a relatively small grants budget, which is inadequate to meet the needs of the beneficiary community. We undertook to apply our remaining reserves to fund more substantial grants programmes over the next 3 years, but still required the additional funding from the Department in order to do so. Our inability to meet this need remains as a result of continued underfunding.”*<sup>384</sup>

Dr Rowena Jecock replied on 11 December 2014 to say:

*“I and colleagues here recognise that your Board may need to consider some difficult decisions on whether to reduce or stop payments, but we are pleased*

382 Letter from Elizabeth Boyd and Russell Mishcon 12 February 2014 p3 WITN1122048. Both CEO and chair had, according to the letter, refused to amend the business case for further funding for the Macfarlane Trust because it would affect the business case of the Caxton Foundation (of which Jan Barlow was also chief executive) for parity.

383 Roger Evans Transcript 5 March 2021 pp56-57 INQY1000105. In a revealing exchange between Counsel and Roger Evans he was asked, as to the events of early 2013: “*was it your sense, either at this time or more generally, that the Board of the Macfarlane Trust was fractious and dysfunctional?*” He replied: “*Well, we were going through a difficult time, largely because two of the three proponents of [the letter discussed at the board meeting in January 2013], and Kate Evans was not one of them, were making the functioning of the Macfarlane Trust Board very difficult. I’m very happy in other ways to elaborate on that but it’s quite a big issue and I wasn’t sure whether that might have been the incentive between suddenly producing [the letter] for signing and threatening resignation, rather than anything entirely to do with funding.*” He did not dispute the words “*fractious*” and “*dysfunctional*” but accepted them; and was prepared to be suspicious of their motives. There seems little doubt that a degree of personal distrust was reciprocated. Roger Evans Transcript 4 March 2021 p88 INQY1000104

384 Letter from Roger Evans to Dr Rowena Jecock 5 November 2014 pp1-2 MACF0000061\_067

*that you are considering now what would be necessary to achieve financial balance. We appreciate that you have been managing the shortfall between Trust expenditure and departmental funding thus far by using the Trust's reserves, and that this is not sustainable long-term. We have discussed the financial position of the Trust on a number of occasions over the past few years in the context of the significant and increasing pressure on the Department's central budgets. As you know, we have expressed our concern previously about the sustainability of the Trust's payment schedules."*<sup>385</sup>

In her oral evidence, Dr Rowena Jecock did not accept that this last sentence was a warning shot across the bows by the Department of Health to Macfarlane, to say that they might not get the money they wanted if they went on making payments at the level that they currently were.<sup>386</sup> While that may not have been Dr Rowena Jecock's intention in writing in that letter, it is difficult to read the words in any other sense: it is how they would have been understood by the Trust. By way of comment, there is a certain irony in the Department of Health saying to the Trust that on the one hand it is reducing funding to the Trust on account of its reserves, only to then refuse to increase funding once the reserves have been run down.<sup>387</sup>

By October 2015 the Trust's position had become serious. It was made clear to the Department of Health in a meeting that, leaving £750,000 in reserve in accordance with reserves policy, there was only enough money to supplement the annual allocation for disbursements until March 2017. In the event that there was no increase in the allocation by the Department of Health after March 2017, then payments to beneficiaries would need to be reduced.<sup>388</sup>

However, by the end of 2016 it was plain that the writing was on the wall for the Trust. It would continue to operate for a while during the financial year 2017/2018, and for that period the Department of Health intended to provide quarterly allocations. However, it was made clear to the Trust that during that period it would be expected to use up much of its reserve.<sup>389</sup>

## Decisions as to the allocation of funds

Each of Peter Stevens, Christopher FitzGerald, and Roger Evans in turn considered that the Trust should not have been set up as it had been, to distribute inadequate funds to a needy group of beneficiaries on a discretionary basis.<sup>390</sup> The history set out above shows they

385 Letter from Rowena Jecock to Roger Evans 11 December 2014 MACF0000061\_066. See for example, Minutes of the Macfarlane Trust Annual Review meeting 28 November 2012 p3 MACF0000061\_081, when this had been discussed.

386 Dr Rowena Jecock Transcript 13 July 2022 pp150-152 INQY1000226

387 It is fair to point out that there still was a reserve, and one remained until the Trust ceased to function when EIBSS was established.

388 Minutes of Macfarlane Trust Annual Review 2014/15 meeting 16 October 2015 p2 MACF0000061\_053

389 Report from Macfarlane Trust Chief Executive to Trustees 30 January 2017 pp2-3 MACF0000027\_066, Letter from Alasdair Murray to Ailsa Wright 10 February 2017 MACF0000061\_050

390 A very clear theme of the evidence, from Peter Stevens in particular, was the difficulty imposed on the Trust by its inadequate funding and inadequate assurance of further funding. I accept the submission made to the Inquiry on behalf of the clients of Milners Solicitors that "*clarity of aims and eligibility, as*

were right on this. Almost from its inception, difficult decisions had to be made to safeguard the remaining funds for what were thought more deserving cases. A dichotomy was quickly drawn between “primary” and “secondary” beneficiaries. The Trust deed itself drew no such distinction. It was the board, therefore, which made a judgement<sup>391</sup> as to which group was more deserving.<sup>392</sup> It understandably regarded those who had been infected by HIV as the primary group, since others traced their qualifications to be beneficiaries by reference to their being in a relationship with an infected person (whether familial, spousal, dependent, or caring), but the distinction was not one based fairly and squarely upon demonstrated need.

If it were to be a charity, the Macfarlane Trust could not distribute funds for any purpose which was not charitable. The governing deed required a beneficiary to be “needy”.<sup>393</sup> However, the trustees interpreted “needy” as “financially needy”. They did not have to do so. The limitations of taking such a restricted view of what “needy” meant became apparent when the Trust had to grapple with applications by married couples for assistance with costs involved in helping them to have a child without unreasonable risk to mother and baby.<sup>394</sup> However, so far as financial need (as such) was concerned, the trustees (with some uncertainty) made some payments on a regular basis, to some beneficiaries. They hoped that this would best enable beneficiaries to choose their own priorities for expenditure. The amounts which recipients of this “regpay” were given differed. They depended on the category in which a given recipient was placed. The distinctions between categories did not directly relate to financial need though that was supposed to be the sole governing criterion. By mid 2002, the tariff of different categories was such that Peter Stevens described it as complex – there were then 15 different rates applicable to single or married men before taking account of children – such that establishing the appropriate rate used up office time, encouraged inaccuracy, did not recognise different financial needs arising from family circumstances, and allowed inconsistencies to arise.<sup>395</sup>

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*well as clear income streams and/or the ability to have guaranteed financial payments from the state, would have provided a surer system to provide financial support, and may have avoided some of the unhappiness and turmoil that the MFT’s system created. In the words of WITN1387, who was a user trustee, the MFT ‘could have been a vehicle for good but in the end, all it did was generate bitterness and heartache and was at the end, an arm’s length organisation’.* Closing Submission of Milners Solicitors 16 December 2022 p174 SUBS0000055

391 Albeit informed by advice from the Trust’s solicitors, which may have suggested only limited help to parents. Minutes of Macfarlane Trust Trustees meeting 14 March 1989 pp3-4 MACF0000002\_014

392 See a paper annexed to the minutes of the trustees meeting of 28 September 1989: Minutes of Macfarlane Trust Trustees meeting 28 September 1989 p25 MACF0000002\_018. It considered that the trustees needed to consider how they could decide who was “needy” amongst widows and dependants. In its discussion of this it shows that they believed that the Department of Health itself favoured a distinction between “primary” and “secondary” beneficiaries – it considered that spending money on members of the second group was “the area of expenditure most vulnerable to criticism by our paymasters as encroaching on the grounds of compensation, and thus could in time affect any decision to allocate further funds” because (summarising) “The Trust was established to cater for the special needs of people with haemophilia in connection with HIV and AIDS” and “The state benefits system exist to take care of need (vs poverty). (Whatever we may think of the level it chooses).”

393 Trust Deed constituting the Macfarlane Trust 10 March 1988 clause 4 p5 MACF0000003\_064

394 The way in which the Trust handled this issue is explored in some detail in the section below.

395 Proposals for revision of structure of grant payments 18 July 2002 MACF0000011\_072

Though regpay was in principle a sensible approach, not all of the fund could be expended in this way without reserving a proportion to meet particular individual needs. The greater the sum spent on regpay, the more beneficiaries were enabled to meet the cost of the particular needs they individually felt it important to prioritise. But the greater the sum spent on regpay, the less was the sum available to meet unforeseen individual needs or the needs of those not entitled to seek regpay. Establishing the priorities by which those needs were to be assessed so that one-off (single) grants could be paid from such a limited fund thus became critical, but this objective was never properly achieved.

Inconsistent though regpay decisions in the early 2000s were, as described by Peter Stevens, decisions as to single (one-off) grants were yet more so. At some date which was not clearly established, a practice began of the office staff deciding applications – where they were relatively straightforward<sup>396</sup> – and by a sub-committee of trustees where they were either less obvious, and the staff felt they should refer the application to the sub-committee, or where the staff were inclined to turn them down. This sub-committee was known as the Allocations Committee. It became the subject of criticism by beneficiaries, as the evidence mentioned above (especially from Susan Daniels and Jude Cohen) shows, and its replacement by the NSSC was welcomed by the Kingston Smith review.<sup>397</sup>

Throughout, however, there was a lack of openness and transparency. This was despite a number of “wake-up calls”, and despite the fact that each witness who had been involved in running the Trust who was asked in evidence about the criteria and processes accepted that they needed to be open, transparent, and fair.<sup>398</sup>

The absence of sufficient information for beneficiaries stemmed from a misplaced distrust of them by the trustees, expressed as a fear that if the beneficiaries were told more they might abuse the system, or their claims might exceed the funds available to the point of leaving insufficient for future applicants.<sup>399</sup> This distrust led to policies which demanded that need be established in some detail, and that two or three quotations were to be obtained.<sup>400</sup> From 1990/91, the policy, too, was to restrict grants to “*health related*” issues.<sup>401</sup> This was because, as from that time, regular monthly payments were increased in value – giving

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396 Initially not to exceed £500. This must have been before November 1988, for by then the Allocations Committee recommended that the administrator and social worker be authorised to make larger payments of up to £1,000 and the trustees agreed. Minutes of Macfarlane Trust Trustees meeting 24 November 1988 p3 MACF0000002\_010. In January 1989 the Allocations Committee reported that this “*now allowed the Allocations Committee more time to resolve complex cases in greater detail and thus to help develop policy.*” Minutes of Macfarlane Trust Trustees meeting 17 January 1989 p3 MACF0000002\_012

397 Report on the Grant Making Procedures of The Macfarlane Trust 18 April 2005 pp9-10 MACF0000014\_001

398 Peter Stevens Transcript 23 February 2021 pp151-168 INQY1000098, Roger Evans Transcript 5 March 2021 pp1-5 INQY1000105, Jan Barlow Transcript 3 March 2021 p25 INQY1000103. All bar Jan Barlow were asked about them also needing to be consistent, though it is clear that being consistent is usually part of being fair.

399 Peter Stevens Transcript 23 February 2021 pp156-157 INQY1000098. This distrust was one side of the mutual distrust which Susan Daniels and Jude Cohen identified in evidence.

400 Peter Stevens Transcript 23 February 2021 pp158-160 INQY1000098

401 Macfarlane Trust *Newsletter No10* April 1991 p4 MACF0000005\_023

recipients greater choice over what they might spend money on, and permitting the trustees to adjust the one-off payments better to favour those with greatest financial need. This policy implied, however, that proof of a health-related need should be supplied, and this involved both financial details being required and the support of a medical consultant.<sup>402</sup> There was, however, no clear guidance on what would be considered a “*health related*” issue.<sup>403</sup>

For ease of administration, office staff were permitted to authorise grant applications in accordance with broad “office guidelines”. However, these guidelines were not published to the beneficiaries. Though Christopher FitzGerald said that in his time the office guidelines were available to all,<sup>404</sup> Peter Stevens said that no guidelines were published because “*they became shopping lists*” if that was done, though explanations of the policy could be gained from the handbook, newsletters and from the website. Asked “*Why did you think that the publication of guidelines would result in a shopping list, by which I assume you mean applications being made that were unmeritorious?*”, Peter Stevens replied: “*That’s what happened. We’re dealing with people.*”<sup>405</sup> His view was also that if a guideline had provided, say, for the purchase of a mattress up to a particular maximum sum, there would instantly be a lot of requests for that sort of mattress, costing that sort of money.

Those seeking single grants were required to ensure that funding for, or provision of, the item required was not available from some other source. The trustees’ view was that recourse to the Trust should be the last resort.<sup>406</sup> Peter Stevens wanted applicants to come to the Trust, but only after they had tried anywhere else that might help.<sup>407</sup>

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402 Peter Stevens Transcript 23 February 2021 pp163-166 INQY1000098

403 A wide view might have been taken – that a lack of educational opportunities consequent on HIV leading to a lack of high-level employment, leading to a comparative shortage of income, and an inability to afford to meet unforeseen payments as necessary, would be “*health related*”.

404 “*available*” does not however mean circulated or published. Christopher FitzGerald Transcript 26 February 2021 pp57-59 INQY1000101. Indeed, his valedictory edition of *Macfarlane News* supports this view. Whereas Macfarlane Trust discretionary “top-up” payments to top up the annual net household income (which varied depending on the level of income) were specified for each income band, there is no useful detail in respect of when and for what a discretionary grant may be sought, or the criteria for making it. Under the heading “*Payment Increase – the Macfarlane Trust – Discretionary Payments*” the Newsletter simply says “*Please refer to the support services section.*” That then takes a reader to the previous page where there is a heading “*From Support Services*”. There, under the heading “*Grants*” it reads: “*Although we stopped providing grants under the office guidelines, it should be noted that where exceptional circumstances can be shown, the NSSC (National Support Services Committee) will consider grant requests from primary beneficiaries and the bereaved community.*” This does not define what is exceptional; and gives no useful indication of who can apply for what and when or in what circumstances; and although it says “primary beneficiaries” and the bereaved community may apply, it suggests that no application from family or dependants outside that category will be entertained, even though they are in the list of beneficiaries set out in the Trust Deed. *Macfarlane News* Spring Edition 2012 pp3-4 MACF0000268

405 Peter Stevens Transcript 23 February 2021 p157 INQY1000098

406 Peter Stevens regarded this as a consequence of the way in which the Macfarlane Trust had been set up.

407 Though in the case of a charity with limited funds there can be no complaint about a policy which would seek to secure funding for a beneficiary from other available sources, it was not justifiable to do as was done in the case of the Macfarlane Trust and place the burden on a grant applicant in poor health to show that none was available in their case. If such a policy was to be adopted, it needed dedicated support workers who could find this out for the applicant, and do so quickly.

Regpay required the completion of a census form setting out, in broad terms, household income,<sup>408</sup> and single grants required:

- (a) other sources of potential funding to have been exhausted;
  - (b) three quotes to have been obtained;
  - (c) sometimes the submission of details of household income and expenditure;
  - (d) usually the support of a medical practitioner (normally the applicant's haemophilia clinician);
- and
- (e) there was no clarity as to the precise criteria by which an application would be judged; nor
  - (f) the maximum amount which might be allowed.

With requirements of this nature, it is not difficult to understand why applying to the Trust for support was not only seen as bureaucratic but also as demeaning, intrusive, demotivating and embittering. Furthermore, if an application were rejected, what then? There were no published criteria setting out the basis on which an appeal might succeed.<sup>409</sup>

Assistance could be, and often was, sought from the office. But there could be no guarantee that what one applicant was told would necessarily correspond with that which was said to another.

Though the NSSC which made the more difficult decisions on single grants was said on external review to be an improvement in process,<sup>410</sup> it was far from perfect.

### **Assisted conception**

One of the issues which epitomises the way in which difficulties for beneficiaries were made worse than they needed to have been, with distressing consequences, was the issue of assistance with conception. A profound consequence of infection with HIV was the impact on the ability to have a child: there was a real risk that the mother, or baby, or both would become infected: yet few matters are more fundamental to many women, many men, and many couples.

The question of grants to enable artificial insemination had been raised at an early stage in May 1988.<sup>411</sup> Following an initial decision in July 1988 that no such payments would be

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408 This was not necessarily completed annually, but often at longer intervals. It was said to be designed to ensure that the Trust was kept broadly aware of changes in financial circumstances. Peter Stevens Transcript 23 February 2021 pp160-161 INQY1000098

409 Peter Stevens Transcript 23 February 2021 p163 INQY1000098, Jan Barlow Transcript 3 March 2021 p50 INQY1000103, Jude Cohen Transcript 11 March 2021 pp77-78, p84, pp183-184 INQY1000108

410 Report on the Grant Making Procedures of The Macfarlane Trust 18 April 2005 pp9-10 MACF0000014\_001

411 Minutes of Macfarlane Trust Trustees meeting 9 May 1988 p3 MACF0000002\_004



made, further discussion, and the lack of a “*clear consensus on the matter of principle*”, led to the position that individual cases were considered on an ad hoc basis.<sup>412</sup> Thus, in the early 1990s the Macfarlane Trust did make some payments to couples wishing to have a child without risk of infection to the mother: typically, a contribution towards the cost of donor insemination treatment.<sup>413</sup> In other cases it did not. By November 1994 there was clearly some discomfort at this position, with the trustees recognising that “*there was no valid way to treat different applications on individual merit and that a decision on principle was needed.*” The minutes of the board’s meeting record the rejection of “*any consideration other than strictly financial*” and on this basis the trustees voted “*4-4 on whether the Trust should regard such payments as a high enough priority for use of Trust funds.*” No application for assistance having at that stage been approved for a considerable period, the chair voted that this was the status quo and gave his casting vote for no change.<sup>414</sup>

At some point in the course of 1995 the Trust “*suspended*” the making of any such payments.<sup>415</sup> In March 1995, John Williams explained the Trust’s decision to make no grants. He gave two distinct reasons: the second reason was financial (“*With a constant need to look to the future and ensure the maintenance of resources for emergency care, the Trustees are most reluctant to accept any open-ended commitment*”) but this was, he said, less important than the first reason, which he explained in these terms: “*For the Trust to give universal help would be in effect to imply total endorsement of the principles involved. Not only are the Trustees less than unanimous on this point, they also fear that automatic support may in practise nudge more people into making a decision which they might not have made if left to themselves, and which some might sooner or later regret.*”<sup>416</sup> By way of comment, this explanation is not consistent with the minutes from the board’s November 1994 meeting, which had rejected any consideration other than the strictly financial. It is also patronising.

The issue of whether the Trust should fund assistance with conception was then discussed at the UK Haemophilia Centre Directors’ Organisation (“UKHCDO”) meeting in September 1995, where a third reason emerged. Dr Andrzej Rejman reported on that discussion to colleagues within the Department of Health: “*The Trust had pointed out that it did not have unlimited finances, and questioned whether producing more children which would lead to greater costs for the Trust in the long term was appropriate. One of the Haemophilia Directors pointed out that the Trust would then need to support the children that they had helped to be born ... It was felt that individual Directors should write to the Macfarlane Trust giving their views about whether this was an appropriate use of money.*”<sup>417</sup>

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412 Minutes of Macfarlane Trust Trustees meeting 20 July 1988 p1 MACF0000002\_006. At its August 1988 meeting the board agreed that specific cases would be brought to the attention of Dr Peter Jones who would make recommendations “*after identifying what other sources of help were available.*” Minutes of Macfarlane Trust Trustees meeting 22 August 1988 pp1-2 MACF0000002\_007

413 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p6 WITN1090026

414 Minutes of Macfarlane Trust Trustees meeting 22 November 1994 p5 MACF0000017\_044

415 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p6 WITN1090026

416 Letter from John Williams to Dr Christine Lee 15 March 1995 MACF0000078\_014

417 Note of UKHCDO meeting 29 September 1995 DHSC0003186\_009. The UKHCDO minutes do not identify who questioned the appropriateness of funding, merely recording that there was “*some discussion on IVF [in vitro fertilisation] and AID [artificial insemination with donor semen]*” and that

In October 1995 Amanda Beesley, whose husband Andrew had been infected with HIV through the treatment he received whilst at Treloar's, wrote to the Trust regarding its policy not to provide grants towards the costs of assisted conception. Her letter powerfully expressed the position she, and others, found themselves in:

*“One of the most distressing aspects of living with HIV is the inability of couples to have a family without risking wives and off-spring becoming infected. This is not simply about couples wanting a baby as some sort of possession but is about bringing a sense of purpose to life, of seeing a continuation of self, of keeping pace with peers. (The latter point may seem trivial but the isolation a couple can experience when all their friends have children should not be under-estimated ...)”*<sup>418</sup>

She referred to techniques being pioneered in Italy (involving sperm washing)<sup>419</sup> and its associated costs, pointing out (rightly) that *“None of this would have been necessary if my husband had not contracted HIV from infected blood products”*, and appealed to the Trust *“to help wives like me to feel we could have some chance of sharing the joy of parenthood with the partner we have shared so much suffering with.”*<sup>420</sup>

The minutes of the trustees' meeting in November 1995 reported that they *“again considered the subject of assistance with conception ... most of the reservations previously expressed still applied.”* However, trustees accepted that the subject continued to be raised, and favoured a *“firm policy ... which could delineate what the Trust would or would not do without involving itself in any ‘judgmental’ differentiation between one case and another and which could therefore be defended in public should this be necessary.”*<sup>421</sup>

John Williams thus wrote to Amanda Beesley in December 1995 to explain that trustees had not come to a final decision on the question of assistance with conception at their November meeting. He hoped a decision would be made before the trustees' next meeting, but thought any change to *“their earlier exclusion”* was unlikely to include any treatment outside the UK.<sup>422</sup>

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individual directors might write to the Trust if they wished to comment. Minutes of UKHCDO meeting 29 September 1995 p5 HCDO0000495. Since a decision as to funding was one for the Trust alone, it might be thought surprising that UKHCDO were discussing a matter which was not directly related to treatment, and with which they had no power to deal. However, it might be that UKHCDO doctors could help to signpost those of their patients who wanted help to have a baby to sources of funding, one of which potentially was the Trust.

418 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p1 WITN1090026

419 A study co-authored by the clinicians in Milan offering this service reported that *“Those who successfully conceived reported a positive impact on their quality of life, fulfilling their desire to be parents and restoring their sense of ‘normalcy.’”* Sunderam et al *Safe conception for HIV discordant couples through sperm-washing: experience and perceptions of patients in Milan, Italy* Reproductive Health Matters 28 May 2008 p2 RLIT0002302

420 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p1 WITN1090026

421 Minutes of Macfarlane Trust Trustees meeting 21 November 1995 p5 MACF0000017\_049

422 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p3 WITN1090026

At the trustees' February 1996 meeting, Dr Elizabeth Mayne informed fellow trustees that her inquiries had revealed that, contrary to expectation, artificial insemination had a very low success rate and that sperm washing could possibly be considered as an alternative. She said *"the more she talked to different people, the more she realised that our members did need help."* The trustees voted to change their policy and contribute towards the cost of private assisted reproduction treatment, provided such treatment was approved by the Human Fertilisation and Embryology Authority and available from the NHS, but not to support experimental treatments or treatment outside the UK.<sup>423</sup> This excluded sperm washing which was not then available in the UK.

John Williams wrote to Amanda Beesley in April 1996, explaining that whilst trustees had *"moved some way forward to a more positive response to this type of request, I am afraid there are still some reservations in this respect and I have been attempting some further discussions."* He explained that assistance towards the costs of sperm washing would not *"fall into the Trustees' criteria ... the Trustees are concerned that to give financial support implies an acceptance/endorsement of the process if not an actual recommendation, and they are therefore reluctant to be involved with anything experimental, particularly if it is not accepted by the National Health service. (or in this case by the Human Fertilisation Embryology Authority either)"*. It is clear that he was sympathetic towards the request: *"your views are entirely tenable even though they do not coincide with the present views of the Trustees ... All I can promise for the moment is that we will raise the matter again with the Trustees and see if we can persuade them to widen (rather than move) the goalposts."*<sup>424</sup>

Amanda Beesley wrote again to the Trust on 16 April 1996, expressing frustration both at the length of time the trustees were taking to consider these matters and at the substance of their position:

*"I was of course disappointed to read that the Trustees were still not agreeing to help couples who wished to go to Dr. Semprini's clinic in Milan, especially as it has taken six months for them to reach this decision during which time, my husband's health has deteriorated. I think that the committee need to keep to the forefront that they are dealing with requests from a population who do not have time on their side ... We do not have the time available to wait for Dr Semprini's procedure to be adopted by the NHS, we have to proceed **NOW** whilst my husband is still alive. Why can the Trustees not treat me as an adult capable of assessing risk to my health and support me in taking what I consider to be the safest option of conception? ... The drive to have children is very strong in many women, possibly in the majority. Women who know they are likely to lose their partners early in life are perhaps more strongly driven than others. This is because we know we are in a race against time and because we desperately want to have a child who*

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423 The Trust would contribute 75% of the cost towards one course of treatment only, up to a maximum of £1,000. Minutes of Macfarlane Trust Trustees meeting 8 February 1996 pp5-6 MACF0000017\_050. Between the adoption of the policy and January 1999 the Trust provided grants for fertility treatment to six couples. Letter from Ann Hithersay to Sarah Chandler 5 January 1999 p2 MACF0000003\_009

424 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p8 WITN1090026

*will enrich our time with our partners and will continue to be a living testament to them after they die ... I believe that women who are desperate to have children can become desperate enough to take risks (indeed I have met some who have). The Trustees need to accept that this is the case and help couples wanting to be treated by Dr. Semprini rather than contributing to the likelihood of risk taking by refusing to support attempts to conceive more safely.”*<sup>425</sup>

A trustees’ meeting in May 1996 discussed correspondence received from three wives (including, no doubt, the above letter) regarding the Trust’s policy. The minutes record that “*Discussion on these called into question whether the current Trust guideline was adequately formulated or would be only theoretically a help to anyone, and also on whether ‘sperm-washing’ was or was not gaining acceptance within the UK as an acceptable treatment as opposed to an experimental process.*” The Trust agreed to take up an offer by Dr Mark Winter to seek expert advice.<sup>426</sup>

Following that meeting, Reverend Tanner wrote to Amanda Beesley to the effect that the trustees “*did not agree to extend the terms under which they are prepared to assist with the costs of reduced-risk conception.*” The letter explained that the decision “*ultimately rests on what the Trust could and can do with its limited resources*” and that “*One call on Trust resources that has never been accepted is for medical treatment of any kind, either for people registered or for members of their families.*” This latter point was plainly incorrect, as the policy agreed in February 1996 did – in principle at least – agree that contributions could be made towards the cost of some assisted conception treatments.<sup>427</sup>

The position remained unchanged<sup>428</sup> and unreviewed until, prompted apparently by a letter from Dr Winter, the Trust looked at the position again in September 1998. The minutes of this meeting recorded that a number of centres in the UK were now providing treatment that made it possible to use the infected partner’s sperm with a significantly reduced risk of the infection being passed on to mother or child. “*Trustees discussed issues raised and felt that*

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425 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p9 WITN1090026. Emphasis in original. In a further letter on 10 May 1996 Amanda Beesley drew attention to the fact that the Human Fertilisation and Embryology Authority had recently agreed to HIV discordant couples having IVF treatment. Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p12 WITN1090026

426 Minutes of Macfarlane Trust Trustees meeting 21 May 1996 p6 MACF0000017\_052

427 Letters between Amanda Beesley and Macfarlane Trust October 1995-June 1996 p13 WITN1090026. The impact of the delay in the Trust’s decision making, and of its refusal to fund sperm washing, for Amanda and Andrew Beesley was described during her oral evidence to the Inquiry. Having managed to fund themselves a first, unsuccessful, attempt at sperm washing in Milan, and having been refused any further assistance by the Trust, they heard that sperm washing was to be made available at a London hospital and decided to wait for that programme to commence, which they understood, in April 1996, would be in approximately three months time. There was then a prolonged delay in the programme beginning. Amanda received the letter inviting them to attend the clinic for sperm washing two days after Andrew died in March 1999. She told the Inquiry “*I was, and still remain, deeply saddened that I was never able to have a baby with Andrew.*” Written Statement of Amanda Beesley paras 58-59 WITN1090001, Amanda Beesley Transcript 16 October 2019 pp123-129 INQY1000042

428 In February 1998 the Trust considered and rejected an application for funding from a hospital medical school which was undertaking research into sperm washing, on the basis that the Trust Deed restricted payments to those of direct benefit to members. Minutes of Macfarlane Trust Trustees meeting 10 February 1998 p6 MACF0000005\_041

*legal advice would be necessary on whether or not Trust funds should continue to be used ‘to create more Trust dependants’. It was suggested that there was a fundamental right to have a family and that it was therefore a choice that the Trust could enable Registrants to make.”* The outcome was that the chair would report the discussion to Dr Christine Lee, as he understood that UKHCDO was considering the matter, that he would raise the matter with the Trust’s solicitors,<sup>429</sup> and that he would report back to trustees in November.<sup>430</sup> At the Trust’s November 1998 meeting, Dr Winter proposed taking a test case to a health authority for funding, and preferred to await the outcome of such a test before making recommendations to the Trust on future policy changes.<sup>431</sup>

In January 1999 Ann Hithersay expressed the view that *“from the point of view of the Trust, I believe the issue is whether or not ‘to found a family’ is a valid ‘need’ to be met in accordance with the Trust Deed ... there is little doubt that our Registrants would consider this a valid ‘need’; as such Trustees will need to devote more time to this issue.”*<sup>432</sup>

In February 1999 (by which time sperm washing was available in London<sup>433</sup> and at a number of other fertility centres in the UK), the trustees again reviewed the position. Dr Winter reported that some health authorities would consider applications for funding such treatments and advised that the funding was the responsibility of the NHS; the minutes record that *“It would be unwise for the Trust to take on the funding of treatments as such.”* Trustees agreed that at the present time no further grants should be made for treatments.<sup>434</sup> No grants for sperm washing having been made at all by the Trust by that time, the agreement that no *“further”* grants should be made for treatments might suggest a reversal of the previous policy that grants could be made towards treatment involving donor insemination. Later documentation confirms that this was indeed the Trust’s position.<sup>435</sup>

In April 2001 the trustees decided against a change of policy relating to sperm washing, but recognised that the wish to have children was *“an important issue”*: the working group looking at Trust strategy would consider it and make further recommendations in due course.<sup>436</sup> A report produced by Claudette Allen, a social worker for the Trust, recommended that the Trust should start to provide financial support for sperm washing; she pointed out too that people did not have *“the luxury of unlimited time, so getting funding is a matter of some urgency and importance.”*<sup>437</sup>

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429 It is apparent from a letter from Ann Hithersay on 5 January 1999 that the Trust did consult solicitors. Letter from Ann Hithersay to Sarah Chandler 5 January 1999 MACF0000003\_009

430 Minutes of Macfarlane Trust Trustees meeting 15 September 1998 p5 MACF0000017\_064

431 Minutes of Macfarlane Trust Trustees meeting 24 November 1998 p4 MACF0000017\_065

432 Letter from Ann Hithersay to Sarah Chandler 5 January 1999 p2 MACF0000003\_009

433 Request for financial assistance: Risk-reduced conception 23 February 1998 MACF0000005\_137

434 Minutes of Macfarlane Trust Trustees meeting 23 February 1999 p4 MACF0000017\_066, Report from Dr Winter on Infertility Treatment for HIV Discordant Couples MACF0000005\_017

435 That the Trust had ceased to fund all treatment including donor insemination is clear from a 2001 report from the Trust’s social worker and a 2002 report from Ann Hithersay. Assisted Fertility Treatment report 2001 MACF0000006\_132, Proposal to Fund Ancillary Costs of Fertility Treatment 23 July 2002 DHSC0002974\_002

436 Minutes of Macfarlane Trust Trustees meeting 24 April 2001 p7 MACF0000006\_003

437 Assisted Fertility Treatment report 2001 p1 MACF0000006\_132

The matter was considered again by trustees in October 2001: it was agreed that Dr Winter would try to find out more about treatment success rates and health authority funding. The issue “*would be deferred to the next meeting of the Trustee Board for decision.*”<sup>438</sup>

No decision on the issue of principle was actually taken at the next meeting. In May 2002 it was agreed that the Trust would write to each health authority to ascertain its policy on funding fertility treatment for HIV positive couples, and that it should also “*put pressure on the Department of Health to provide funding for fertility treatment for Trust registrants and should call upon the UKHCDO and the Haemophilia Alliance to support this move*”. The Trust should “*be prepared to fund ancillary costs relating to treatment and should also assist couples to apply for Health Authority funding and to appeal against decisions not to fund*”. However, it was agreed that a final decision would be taken at the next meeting in July.<sup>439</sup> A decision was thus deferred again.

In July 2002 Ann Hithersay sought approval for an annual budget for ancillary costs relating to fertility treatment.<sup>440</sup> On 30 July, having considered Ann Hithersay’s paper, trustees agreed that the ancillary costs of fertility treatment could be funded and that costs up to a maximum of £2,500 per couple would be met by the Trust.<sup>441</sup> It remained the Trust’s position that treatment costs should be funded by the NHS: the ancillary costs would cover expenses such as travel and subsistence.

In 2003 Hilary Barnard’s Long Term Review report recommended that there should be direct support to registrants for assisted conception “*and lobbying for all parts of the NHS to recognise that funding of assisted conception for registrants and their partners is a justified claim that should be met from the public purse.*”<sup>442</sup>

By August 2004 it nonetheless remained the position that the Trust only funded ancillary costs. At a board meeting that month it was noted that any change in policy would be a “*major shift in the nature of support given to the registrant community*” and it was resolved to defer the matter for considered debate by the NSSC.<sup>443</sup>

That debate happened when, in January 2005, the NSSC recommended that the board should adopt a new policy on financial support towards assisted conception: that applicants should attempt to obtain through the NHS as many of the tests and procedures as available; that the NSSC would consider applications towards a maximum of three cycles of sperm

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438 Minutes of Macfarlane Trust Trustees meeting 23 October 2001 p6 MACF0000006\_001. The Trust’s solicitors advised it in October 2001 that the objects of the Trust were sufficiently wide to cover funding for fertility treatment and that it was open to the Trust to meet the costs of such treatment even if available on the NHS. Letter from Gillian Fletcher to Ann Hithersay 11 October 2001 p3 MACF0000006\_123

439 Minutes of Macfarlane Trust Trustees meeting 28 May 2002 pp6-7 MACF0000011\_003. A representative from the Department of Health, Robert Finch, was in attendance at the meeting.

440 Proposal to Fund Ancillary Costs of Fertility Treatment 23 July 2002 DHSC0002974\_002

441 Minutes of Macfarlane Trust Trustees meeting 30 July 2002 p7 MACF0000011\_004

442 The Macfarlane Trust Long Term Review A Full Life – Not Just Existence October 2003 p36 MACF0000172\_001

443 Minutes of Macfarlane Trust Trustees meeting 11 August 2004 p4 MACF0000019\_093

washing at a maximum cost of £2,000 (sperm washing not being available via the NHS); and that the NSSC would consider applications for funding for other aspects of assisted conception where there was evidence that the NHS would not fund these or that there would be inordinate delays due to waiting lists.<sup>444</sup>

The board, however, remained unsure. Following a “lengthy debate” at its January 2005 meeting, which followed the NSSC recommendation, it was resolved in the first instance to ask the Department of Health for its attitude to the difficulties caused by the postcode lottery within the NHS, and to seek approval from the Department of Health regarding the proposal to support registrants in their attempts to “advance conception by assisted means.”<sup>445</sup> Martin Harvey duly wrote to the Department of Health on 31 January 2005. William Connon’s response as Head of Blood Policy on behalf of the Department of Health was that providing additional assistance for registrants to undertake treatment programmes for assisted conception would not be appropriate.<sup>446</sup>

Notwithstanding the correspondence with the Department of Health, the NSSC at its February 2005 meeting reported that its policy recommendation had been agreed and that the Trust policy on assisted conception was as had been proposed in January.<sup>447</sup> This was reflected in the office guidelines for March 2005 which explained that grants could be made for a contribution towards the cost of sperm washing (maximum £2,000) and towards costs related to, but not including, treatment for assisted conception.<sup>448</sup>

Amanda Beesley’s reflection on the Trust’s approach, in her oral evidence to the Inquiry, was telling: “it’s just typical of their approach, really, that they were just a paternalistic organisation and they held so much control over what we could and could not do with our lives ... they just wanted to play God with us, you know, wouldn’t allow us to make our own decisions, you know, which we should have been able to.”<sup>449</sup>

## NSSC from 2008 onwards

In 2008 Neil Bateman, an experienced and effective welfare rights advisor, was asked to advise on a proposed welfare policy. His response was that it was very complicated, and effectively grafted another means test on top of others already undertaken for many welfare benefits. He commented: “as a general principle, it’s not a very good idea to have a separate means test for people who have already been means tested often to death by the DWP

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444 Minutes of Macfarlane Trust National Support Services Committee meeting 5 January 2005 p3 MACF0000014\_069

445 Minutes of Macfarlane Trust Trustees meeting 24 January 2005 pp3-4 AHOH0000003. The decision was one for the Trust to take: but this suggests it thought approval from the Department of Health was necessary, and almost to suggest it was ceding its discretion to the Department of Health.

446 Letter from Martin Harvey to William Connon 31 January 2005 MACF0000014\_049, Letter from William Connon to Martin Harvey 9 February 2005 MACF0000014\_054

447 Minutes of Macfarlane Trust National Support Services Committee meeting 23 February 2005 p2 MACF0000101\_130

448 Guidelines relating to all grant requests March 2005 p6 MACF0000110\_111

449 Amanda Beesley Transcript 16 October 2019 p137 INQY1000042

[Department for Work and Pensions]”; that he was also “concerned that they didn’t seem to – – it didn’t take into account the costs of children and the costs of taking paid employment. And, you know, there’s a substantial – – I mean, one of the things that should happen with any kind of means test, because it does inhibit people taking up paid work, is try to mitigate that as far as you can. And one way is sort of the costs of employment, travel, equipment, that kind of thing”, and “they were proposing sort of step payments, and the problem with step payments is that it creates a cliff edge effect for people. And we get this elsewhere – – we actually get this in places in the social security system, sort of a bit of all or nothing, and it creates terrible problems for folk.”<sup>450</sup>

It was a while later that Roger Evans took over as chair. But he had been a member of the NSSC for several years, and recognised that its process was undesirable as it stood. He described how beneficiaries were essentially subjected to a means test: “in order to obtain even small amounts of money Applicants were required to complete a template in which they listed detailed family information, notably family income, spending habits and circumstances. The system was humiliating and intrusive ... it was not unusual for NSSC to ask for more information, delaying a decision for at least a month. Sometimes they were visited at home.”<sup>451</sup> He understood that it was even suggested that photographs of beneficiaries’ homes should be taken.<sup>452</sup> The following exchange took place: “Q. Do you remember having any concerns about whether that was a fair and appropriate matter to be taking into account? A. Yes, I thought the whole thing was not the right way to go about it.”<sup>453</sup>

Shortly before Roger Evans became chair, a further questionable policy was introduced. The principal criterion for assessing grant applications by the NSSC became one of “exceptional circumstances”.<sup>454</sup> According to Roger Evans, it adopted this approach without first seeking approval from the board, and “exceptional circumstances” were never precisely defined.<sup>455</sup> This lack of clarity and transparency in respect of exceptional circumstances, coupled with their lack of knowledge of what might be applied for by way of grant through the NSSC and how decisions to accept or refuse applications were being taken, caused unhappiness to beneficiaries. Roger Evans said that when he discovered this in 2012 he “very much agreed with them on it”.<sup>456</sup>

What Roger Evans says seems to imply both that the NSSC acted on their own initiative, without the knowledge of the board, and that there was no working definition of exceptional circumstances. Neither of these implications is correct.<sup>457</sup> As to the first, a consequence of the additional provision made after the Archer Inquiry report was that more money would be

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450 Neil Bateman Transcript 12 March 2021 p152-153 INQY1000109

451 Written Statement of Roger Evans para 29 WITN3859001

452 Roger Evans Transcript 4 March 2021 p170 INQY1000104

453 Roger Evans Transcript 4 March 2021 pp174-175 INQY1000104

454 Minutes of Macfarlane Trust National Support Services Committee meeting 10 September 2013 p2 MACF0000024\_145

455 Roger Evans Transcript 4 March 2021 pp177-182 INQY1000104

456 ie with the beneficiaries.

457 Though it may be as he now sees it.



made available for “primary beneficiaries”, making it less likely that they would need financial help for expenditure to meet foreseeable needs. The chair (then Christopher FitzGerald) and Martin Harvey led discussion at a meeting of NSSC in November 2009 that agreed that although wider discretionary support might be made available in exceptional circumstances, this should not be made widely known.<sup>458</sup> In December 2009, the NSSC recommended that single grants to primary beneficiaries should end after March 2010,<sup>459</sup> (which would have meant that whatever the circumstances a “primary beneficiary” would receive no one-off support for any need, exceptional or otherwise) – but the minutes of the board are clear that as far as the board was concerned there remained room for them in circumstances which were unspecified.<sup>460</sup> In mid 2010 the board minutes went so far as to note that: *“grants for the period were low because only the non-infected community could now apply, save for exceptional circumstances. The Chairman asked the NSSC minute taker to ensure that when a grant for a PB was agreed that the exceptional circumstance was noted.”*<sup>461</sup> Roger Evans was present at that meeting, as he was at a board meeting in October 2011 when the chair specifically reminded trustees that *“one of the objects of introducing the policy for discretionary ‘top-up’ payments had been to remove the need both for ‘one-off grants (other than in exceptional circumstances)’ and for ‘across the board’ seasonal payments.”*<sup>462</sup>

I thus cannot accept any implication from Roger Evans’ evidence that the NSSC acted without board knowledge and approval.

As to “exceptional circumstances” there was – eventually, in July 2012 – an agreed definition.<sup>463</sup> It was: *“circumstances that have arisen or are threatened which, in the opinion of the NSSC/Board of Trustees, are unlikely to have been anticipated by a beneficiary in the ordinary course of events and/or it is unreasonable to expect a beneficiary to have to deal with the financial outcome from their normal income.”*

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458 Minutes of Macfarlane Trust National Support Services Committee meeting 4 November 2009 p6 MACF0000128\_024. It is noteworthy that the chief executive’s firm view was that there was a high degree of risk in this approach, that all such requests for support if made would be regarded by the primary beneficiary as exceptional, and that he was *“quite sure the notion of no additional discretionary support was in the primary beneficiary mind-set.”*

459 Minutes of Macfarlane Trust National Support Services Committee meeting 2 December 2009 p5 MACF0000128\_009

460 Minutes of Macfarlane Trust Board of Trustees meeting 25 January 2010 p3 MACF0000015\_067

461 Minutes of Macfarlane Trust Board of Trustees meeting 19 July 2010 p7 MACF0000015\_002. See also: Minutes of Macfarlane Trust National Support Services Committee meeting 7 September 2011 p1 MACF0000023\_049, in which the NSSC asked that the chief executive should state on the website that grants could be awarded in exceptional circumstances.

462 Minutes of Macfarlane Trust Board of Trustees meeting 24 October 2011 p3 MACF0000023\_042

463 Minutes of Macfarlane Trust National Support Services Committee meeting 18 July 2012 p2 MACF0000025\_035. This followed all the members of the NSSC being asked to provide a paragraph giving their view on what constituted *“exceptional circumstances”* and the definition as set out in the text, as proposed by Russell Mishcon, being adopted on 12 July 2012. Minutes of Macfarlane Trust National Support Services Committee meeting 22 June 2012 p1 MACF0000143\_040. The fact that each member was asked for their view shows, however, how imprecise the definition had been until then – if members of the NSSC had different views how could any beneficiary be expected to know what their position was, and whether they could ask or not?

I cannot therefore accept Roger Evans' evidence if it is read as his saying that there had never been a definition – but I do accept that there was no definition until mid 2012 and even then the definition as adopted still lacked precision.<sup>464</sup>

The NSSC had become quite bureaucratic in its approach.<sup>465</sup> Decisions were delayed. Roger Evans described it as having “*introduced some of their own criteria*”<sup>466</sup> (and it led to complaints). Whatever had been the position as to office guidelines before 2011, by now at any rate they simply were not published. The dissatisfaction was such that it reached the ears of Dr Ailsa Wight, deputy director of Infectious Diseases and Blood Policy, at the Department of Health, who referred to it in an email to Roger Evans.<sup>467</sup> Once the board was aware that there was this dissatisfaction he said that they changed the NSSC membership, and established a Grants Committee to replace the NSSC.<sup>468</sup> Nonetheless, it took over 16 months for the Trust to introduce new guidelines for grants.<sup>469</sup> These replaced the previous office guidelines, but the document introducing them said at the start of the text that it was “*intended for internal use only – it will not be distributed to beneficiaries. A summary of the key areas in which grants will and will not be considered will be produced separately as guidance for grant applicants.*”<sup>470</sup> In evidence Roger Evans could recollect no reason why the full document should not have been given to beneficiaries.<sup>471</sup>

By the end of November 2014, the office was given authority to assess income and expenditure individually, and staff referred cases to the Grants Committee where there was difficulty in establishing charitable need. “*Exceptional circumstances*” had been jettisoned

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464 To an extent this may be inherent in any definition of what is to be regarded as “exceptional”. A degree of consistency in application, and predictability of outcome for any applicant, can however be afforded by **guidance** as to the circumstances which so far have been thought to merit that description, so that new applications can proceed to be determined not just by imprecise principle but also by specific analogy.

465 Roger Evans Transcript 4 March 2021 p181 INQY1000104

466 Roger Evans Transcript 4 March 2021 p182 INQY1000104. He added that he had been very unhappy about the position and took some early action to deal with the office issues once Jan Barlow became CEO, “*but it was not easy to convince certain members of [the NSSC] that the approach was a wrong one.*” He said: “*I’m confident that it became a lot better once we made changes in membership and worked towards a Grants Committee.*” As to that, what other evidence reveals is that the NSSC went down to one member as a result of trustee turnover, so Patrick Spellman stepped in to chair it, a Grants Committee was set up, and Patrick Spellman chaired the first three meetings to get it going. Written Statement of Patrick Spellman para 41 WITN3074002

467 Email from Dr Wight to Roger Evans 14 January 2013 p6 MACF0000024\_146. This was discussed in evidence with Roger Evans: Roger Evans Transcript 4 March 2021 pp154-156, pp180-184 INQY1000104, Roger Evans Transcript 5 March 2021 pp1-5 INQY1000105

468 See the previous footnote for how this appears to have come about. The Grants Committee was a third version of the sub-committee whose job it was to determine whether to accept or refuse applications which were not so clear cut that the decision could be made by office staff. The annual report for 2015 acknowledged that the process in reaching decisions on grant applications had sometimes been protracted and suggested that the turnaround of applications was now quicker. The Macfarlane Trust Annual Financial Report for the Year Ending 31 March 2015 pp3-4 MACF0000045\_002

469 A delay of this magnitude is inexplicable, and there is no obvious excuse for it. It suggests an administration either sleeping on the job, or struggling to cope, with inadequate resources to meet demands on staff and trustee time. These are not necessarily alternatives: it might have been a mixture of both.

470 Original emphasis. The Macfarlane Trust Grants Guidelines 2014/15 May 2014 p3 MACF0000171\_042

471 Roger Evans Transcript 5 March 2021 pp11-12 INQY1000105

as a criterion. However, it was unclear against what standards or criteria household income was to be assessed, and to what extent it was “*disposable income*”. It was unclear too quite what the impact of any assessment of disposable income was. There was no consistent practice as to the way in which the income of adults in a household other than the primary beneficiary was taken into account. It was “*common sense, really*” according to Roger Evans (in practice, therefore, the decision might vary with the views of the decision-maker).<sup>472</sup> Household income (whatever use was made of the term) was looked at when considering not only single grant applications, but when assessing regpay, both for primary beneficiaries and widows. When pressed upon the “two quote” principle maintained throughout his chairmanship rather than some more flexible system, he described the principles applied as “*guidelines*” which did not have to be followed to the letter.<sup>473</sup>

Jan Barlow’s evidence confirmed expressly that when she arrived she thought the process of funding single grants was very bureaucratic, that it could take many, many months for people to get a response to their grant applications and that there were difficulties with communications because the whole time people were being asked for more information.<sup>474</sup> She said that “*exceptional circumstances*” criteria were difficult to understand, such that this criterion was abandoned when the Grants Committee succeeded the NSSC; that census forms had to be completed each year – the purpose being to see if the income now fell in a different bracket than previously for the purposes of regular pay – and that people were treated as if they were in receipt of benefits which they had not applied for but would get if they did. Payments from the Skipton Fund (which most infected beneficiaries would have received, because most were co-infected with Hepatitis C) were brought into account in assessing income.<sup>475</sup>

One particular exchange between Counsel and Jan Barlow shows the degree to which decisions as to single grants were subjective and depended upon the view at the time of the decision-maker rather than being based on any policy or guidance:

*“Q. So you had financial information about expenditure and income and outgoings and so on. Equipped with that information, how would the member of the office staff or those sitting on the NSSC assess if it was something that it was reasonable to expect the individual to pay for themselves or not?”*

*A. I say, it was a kind of judgement based on the amount being asked for and someone’s financial position and disposable income.*

*Q. Was there anything by way of guidance as to how that judgement should be exercised?”*

*A. As I said, it was a judgement in relation to the amount being requested in relation to people’s disposable incomes ...*

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472 Roger Evans Transcript 5 March 2021 p18 INQY1000105

473 Roger Evans Transcript 5 March 2021 p25 INQY1000105

474 Jan Barlow Transcript 3 March 2021 pp59-60 INQY1000103

475 Jan Barlow Transcript 3 March 2021 pp56-59, pp61-64 INQY1000103

*Q. ... there wasn't, as a matter of fact, any form of written policy or guidance to decision-makers about how to make that judgement?*

*A. No, not over what I've just described. And, as I say, the reason for that – because you couldn't – it was almost impossible to give an absolute because the equation changed every time.”<sup>476</sup>*

Her evidence was that the Macfarlane Trust had sympathy with the beneficiaries' position in opposing Skipton payments being taken into account when assessing needs associated with HIV. She would have liked to change its policy. However, she thought it would need funds to do so, and when they were not forthcoming the policy simply did not change. In short, what was recognised to be an undesirable policy, likely to cause distress to many of those subject to it, was simply persisted with.<sup>477</sup>

As for taking account of welfare benefits, there was little appreciation of the fact that many such benefits are paid to meet specific needs and are calculated to give little more, if anything, than the minimum required to do so. Instead, child benefit, one such benefit, was taken into account in assessing income for the purposes of the Macfarlane Trust.<sup>478</sup>

Though Peter Stevens, Roger Evans, and Jan Barlow each accepted that the Trust's system for giving grants should be transparent, consistent, and fair,<sup>479</sup> it was neither open, nor consistent. Because the decision-making was opaque and decisions were rarely given in sufficient detail to enable an applicant to know why they had failed,<sup>480</sup> nor were sufficient details given as to the appeal process, it cannot be said that they were necessarily fair. A strong suspicion must exist that individual decisions were unfair since they were reached by a process in which no consistent criteria were applied, and which left too much to the individual views of a staff member or trustee as to what seemed meritorious. On the face of it many of the decisions revealed by the evidence seemed to beneficiaries to be inconsistent with each other. If they were inconsistent they were unfair for that reason alone, whatever other charge of unfairness might also be levelled at them.<sup>481</sup>

It is not a necessary consequence of limited funds that the system for distributing them should be secretive. Though any criteria for distribution would have been open to debate, and their consistent application would have been bound to upset some, establishing them clearly and

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476 Jan Barlow Transcript 3 March 2021 pp34-35 INQY1000103

477 Jan Barlow Transcript 3 March 2021 pp63-64 INQY1000103

478 Jan Barlow Transcript 3 March 2021 p67 INQY1000103

479 See footnote 398. Fairness includes, though is not limited to, being consistent – a system may be unfair in the criteria it sets, though consistent as to the application of those criteria, and might in addition be more unfair still if even those criteria are applied differently on a whimsically inconsistent basis.

480 Or indeed, succeeded. Knowing why one application succeeded was not irrelevant: it would inform subsequent applications.

481 The lack of transparency and openness makes it difficult to be sure that what appeared to beneficiaries to be inconsistent decisions were truly so. If there was an explanation for the apparent inconsistency none was given.

openly would have been far more satisfactory. The process would have been fairer. The result would have been as fair as the more general limitations<sup>482</sup> of the fund permitted.

## Perceptions of an uncaring and dismissive attitude of those running the Trust

The (deliberate) lack of openness and the consequent lack of transparency not only helped to cause, but was accentuated by, the poor quality of personal relations between beneficiaries on the one hand and the chief executives (Ann Hithersay excepted<sup>483</sup>) and a number of the trustees on the other.

Partly, this may have been influenced by the lack of a voice on the board of trustees. Though the Haemophilia Society had a right of appointment of trustees, the early appointees were selected more for their financial acumen or previous public service than for lived experience of haemophilia or infection.<sup>484</sup> Trustees were volunteers, as is conventional, and the first administrator had a background in the armed services. There was only one “user trustee” (ie a beneficiary who was a member of the board) until Ann Hithersay successfully lobbied for their introduction in the early 2000s.<sup>485</sup> Prior to that, a “user trustee” was required to withdraw from trusteeship if they wished to receive any benefit from the Trust.<sup>486</sup> This meant that there was no one with lived experience to help the board.<sup>487</sup> The general evidence was that though some – Peter Stevens being one – made an effort to engage with beneficiaries, particularly in the early days of the Trust when weekends were arranged for beneficiaries to attend and for trustees to come and meet them, for instance over dinner, these fell away, in part through pressures on funding. Engagement after that was first through a Consultative Panel and then through a Partnership Group.<sup>488</sup> This was regarded poorly by at least some

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482 This is a reference to the problems inherent in the way the Macfarlane Trust was set up at its outset.

483 Though some criticism was raised, there was also appreciation: the chief executives who came in for the heaviest criticism by beneficiaries were Martin Harvey and Jan Barlow.

484 Though two individuals, appointed by the Haemophilia Society, were trustees from the first meeting. Both of these trustees resigned in early 1990, after which the Trust became more distant and bureaucratic – compare the tone of *The Macfarlane Trust News* No1 attachment to the minutes from October 1988 with the No4 attachment to the minutes from July 1990. Minutes of Macfarlane Trust Trustees meeting 24 October 1988 pp9-16 MACF0000002\_009, Minutes of Macfarlane Trust Trustees meeting 19 July 1990 pp19-20 MACF0000002\_024

485 Charity law by then had changed so as to permit a trustee who was also a beneficiary to take office.

486 Minutes of Macfarlane Trust Trustees meeting 22 March 1990 pp2-3 MACF0000002\_022. Trust law is such that no trustee may benefit financially from their being a trustee, unless the deed specifically permits it. The Macfarlane deed did not do so.

487 There were trustees – Reverend Tanner and Peter Stevens to name but two – who had lived experience of being affected by the suffering of those infected, and this has not been forgotten. But the point is nonetheless valid.

488 When the board was no longer able to have beneficiaries as fellow trustees, they initially created a Consultative Panel whose work they envisaged would mostly be conducted by post to allow for anonymity and the contribution of minority views. This was explained to beneficiaries as follows: “*How Trust Policies are Decided ... Questionnaires: To augment all this other information the Trustees propose to set up a system whereby the Trust can from time to time canvas views by post on general or specific questions ... if you are willing to help please return the reply slip.*” Minutes of Macfarlane Trust Trustees meeting 19 July 1990 p11, p20 MACF0000002\_024. A Partnership Group first met in May 1999, having been created to meet recommendations from the strategic review: Macfarlane Trust

trustees,<sup>489</sup> possibly because it proved a conduit for complaints about aspects of the way in which the Trust was being administered.

Trustees, for their part, often felt that the beneficiaries did not appreciate that since distributions had to be made on the basis of individual need there had to be some of the elements of the scheme which reflected that.

Very generally put, the trustees and beneficiaries did not see eye to eye. Jan Barlow said that the beneficiary cohort found it difficult to agree amongst itself as to the appropriate approach. A consequence was that the Partnership Group ultimately fell into disuse. The Haemophilia Society again provided a neat summary of this in its submissions: *“the support schemes rarely involved real consultation with those infected and affected, and never took into account the longer-term financial impact on families. Those people and families who were entitled to make claims should never have been made to feel like they were charity cases (as the evidence shows that many did).”*<sup>490</sup>

The absence of any organised feedback or conduit for concerns left individuals to respond in their different ways as between the Trust and beneficiary. For many beneficiaries, who might talk amongst themselves, this was influenced by the way in which some in authority in the Trust expressed themselves. Peter Stevens, in particular, tended to express the distrust he had of the behaviour of others in a forceful and disparaging manner. He recognises that he has made a number of totally inappropriate – indeed, disgraceful – comments, and described some of his longer verbal explosions as *“rants”*.<sup>491</sup> Beneficiaries may not have seen the wider picture which his evidence to the Inquiry coloured in: that he did not exclusively reserve expressing his sense of the shortcomings of others for them alone. He expressed it towards ministers and civil servants as well, politicians and doctors; and about the Government itself. Thus when it was mooted that although the MSPT1 (of £24 million) was non-discretionary and not a charity it should be administered by the Macfarlane Trust, and that the Trust be paid only £19 million up front, being reimbursed later for the shortfall, he described this suggestion by the Government in extreme terms as *“an outrageous suggestion”*, *“absolutely laughable”*, and later that it had come about *“probably through*

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Strategic Review Final Report January 1999 pp19-20 MACF0000045\_019, Minutes of Macfarlane Trust Partnership Sub-Group meeting 14 May 1999 MACF0000007\_204

489 Peter Stevens for instance characterised the Partnership Group as follows: *“If you were to look through the minutes of the various Partnership Group meetings, you will see that there was quite a lot of unpleasant feeling, difficult words that in the end -- I mean, I remember for a while the Partnership Group was chaired by one of the beneficiaries who gave up in the end and said he couldn't stand it any longer. So it was difficult. It all comes back to the same problem, that we were a charity inadequately funded and people had expectations or hopes from the charity that we couldn't possibly, possibly meet. And so they expressed their frustrations, anger, at us rather than the Government because we were the fall guys. We were the people who were in that position and in the end it became -- or it became quite trying on our patience to listen to personal attacks.”* Peter Stevens Transcript 24 February 2021 p38 INQY1000099. Peter Stevens purported to be representing the views of the trustees generally in saying that – *“We were the people”* etc.

490 Closing Submissions of The Haemophilia Society 16 December 2022 para 482 SUBS0000065

491 Peter Stevens Transcript 23 February 2001 p85 INQY1000098, Peter Stevens Transcript 24 February pp34-36 INQY1000099

*political or official idiocy. I mean, it was ludicrous.*<sup>492</sup> He recognised that he ranted, for instance over the Government giving no assurance of funding let alone enough money to be getting on with, in his view with the object of ensuring that beneficiaries blamed the Trust and not the Government for what was government wrongdoing.<sup>493</sup> He speaks (to this day) about them finding money “*down the back of the sofa*”; that “*setting up an inadequately funded charity was the Government’s view of what to do about the people*”; that the decision by Caroline Flint in 2006 to reject his business case calling for £7 million to be paid per annum was “*absolutely outrageous*”; “*typical civil servant smokes and mirrors*”.<sup>494</sup> He had to apologise to a civil servant for his rudeness, and said that he had expressed himself robustly to Caroline Flint in terms which the Inquiry was left to imagine, though he thought them to be language used in Parliament.<sup>495</sup> When he appeared to express distrust of the truthfulness of applications, to the effect that registrants would abuse the scheme unless there were safeguards, Counsel pointed out that it was usually the case they had to have the support of their clinicians. The reply was: “*It would be nice to believe that clinicians were always capable of being objective.*”<sup>496</sup>

However, though he did not single out beneficiaries to be the sole target of his intemperate remarks, they did have a special place in his rhetoric. He referred to the Partnership Group as being a “*lot of moaners*”, and did not object to phrases such as “*the great unwashed*” being used to describe beneficiaries seeking to apply for assistance.<sup>497</sup> The irascibility of his responses was evident when Haydn Lewis sent a private email to him which Peter Stevens agreed was courteously expressed. Despite the email being headed “*Private*”, he forwarded it to Martin Harvey saying “*Notwithstanding the heading, I thought you’d love to join me in starting the week with an insight into the thoughts of Haydn Lewis ... It is irritating that someboyd [sic] so thick can come up with such meddlesome suggestions.*” He agreed this was totally inappropriate, and indeed went to Cardiff to meet with Haydn and his brother Gareth to apologise for his use of language.<sup>498</sup> He had added that, as a result of the letter “*I shall never have a private Email from Haydn Lewis again. Oh happy day! ... ‘Calloo! Callay!’ ... Otherwise, what a monumental waste of time – not just this afternoon, but all the previous hours spent nurturing that lot of moaners.*”<sup>499</sup> In the last document in the series

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492 Peter Stevens Transcript 23 February 2001 pp24-26 INQY1000098

493 Peter Stevens Transcript 23 February 2001 p85 INQY1000098

494 Peter Stevens Transcript 23 February 2001 p84 INQY1000098, Peter Stevens Transcript 24 February 2001 p20 INQY1000099, Peter Stevens Transcript 23 February 2001 pp133-134 INQY1000098

495 This was perhaps a reference to making potentially slanderous allegations under the protective shield of Parliamentary immunity. Peter Stevens Transcript 23 February 2001 p140 INQY1000098

496 Peter Stevens Transcript 24 February 2001 p4 INQY1000099

497 Peter Stevens Transcript 24 February 2021 p37, p29 INQY1000099

498 Email from Haydn Lewis to Peter Stevens 28 November 2004 p5 WITN2368016. He said when asked that he did not know why he talked about a registrant in such terms, adding: “*It’s too early in the morning to say I’ve been drinking so ... Haydn and I had engaged in considerable amounts of considerable email communications and Haydn’s were always long, verbose and quite trying to read at times. So this was the culmination, I think, of a long series of communications with him and it probably just tried my patience.*” Peter Stevens Transcript 24 February p37 INQY1000099

499 That afternoon there had been a meeting of the Partnership Group. Email from Peter Lewis to Martin Harvey 13 December 2004 p2 WITN2368016

he said in an email to Martin Harvey: *“What’s with these people? Funnily enough, when you set it out as you have done, it makes one wonder why infected intimates are treated exactly as registrants since they do not have haemophilia to worry about. We might see if we can review that when we get round to looking at regpay at the NSSC (that would be a way of pissing off the Lewis contingent).”*<sup>500</sup> This he described as making *“a throwaway remark to a friend.”*<sup>501</sup>

In March 2006, a letter he wrote to Clair Walton<sup>502</sup> led to a formal complaint against him.<sup>503</sup> Clair Walton had been receiving an additional payment for some three years. Martin Harvey then told her that this payment would stop. The letter includes a number of passages which are surprising, to the effect that Ms Walton had received considerable sums, that her frequent criticism of the Trust *“appears to ignore this and to assume that we have unlimited resources that we can apply at each and every case – or, at least, to your own”*, that *“You are, of course, entitled to ask us for help. You are not entitled to receive it, any more than anybody else is ... I do suggest that you might give some consideration to the fact you are but one of some hundreds of people who look to us for assistance, many of whom are less articulate than you, do not have the benefit of owning any property, as you do, have dependent families, which you do not, and whose health is much more compromised than your own.”*

Christopher FitzGerald, having recently taken over the chairmanship, met Clair Walton to hear her complaints about the way in which she had been treated and said in a letter of 16 May 2007 that *“whatever sense of frustration or exasperation may have been entertained ... the letter of 13 March 2006 was entirely misguided and misdirected in its tone and approach; in short it should never have been written at all.”*<sup>504</sup>

Comments such as those singled out above became known, and created a perception, especially among those beneficiaries who were in groups which supported each other, that trustees did not care, and did not respect them as individuals. Christopher FitzGerald was right to say what he did in his letter to Clair Walton. Peter Stevens’ letter should never have been written. The damage such comments caused to relations between Trust and beneficiaries was always thereafter likely to be difficult to repair. The fact that the processes adopted for applications for regpay or single grants were as described above, appeared to many beneficiaries to support the perception. They could be seen, with justification, as indicating a lack of care or appreciation for the ill health of beneficiaries, and the social and economic consequences which resulted: to require someone who is ill, or suffering from energy-sapping fatigue, to have first to ask office staff if their application has a chance,

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500 At the time he wrote that he already knew that Haydn Lewis’ wife, Gaynor, was herself infected with HIV. Email from Peter Stevens to Martin Harvey p1 WITN2368016

501 Peter Stevens Transcript 24 February 2021 p42 INQY1000099

502 Beneficiary files of 1823A at the Macfarlane Trust relating to a grievance 13 March 2007: 1823A Grievance MFT 13 March 2007 pp15-16 WITN1589002

503 Though there was no complaint procedure set up by the Trust.

504 Letter from Christopher FitzGerald to Clair Walton 16 May 2007 p2 WITN1589006. He was correct: correspondence like this should never have been written.



then to provide evidence that there are no other sources of support, get evidence that a clinician supports the application, obtain two or more quotes, retain receipts, and be means-tested more than once when they had *“already been means tested often to death by the DWP”*<sup>505</sup> is liable to be seen by those who have already been stigmatised for being ill as being the manifestation of a callous indifference towards them.<sup>506</sup> This approach should not have been adopted.

This landscape undoubtedly influenced reports which reached the Haemophilia Society. Elizabeth (Liz) Carroll became chief executive of the Haemophilia Society in January 2014, without any previous experience as a CEO.<sup>507</sup> She discovered that there was *“not much of a relationship”* between the Haemophilia Society and the Trust. It was not in dispute that she and the CEO of the Macfarlane Trust, Jan Barlow, seldom met before the start of 2015.<sup>508</sup> What then happened is contentious.

At that time, the APPG had just published a report on the operation of the trusts and schemes.<sup>509</sup> Liz Carroll wrote on 10 February 2015 to the Minister, as instructed by the Society, to respond to the publication of their report. The letter recorded that the Society had had *“a great deal of contact with people affected by contaminated blood”* and occasionally met with the chief executive and the chairs of the Macfarlane Trust and the Caxton Foundation. It then said:

*“Although we do receive mixed views on the organisations, the overwhelming experience of those we speak to is dissatisfaction, distress or anger at the way beneficiaries of the organisations are treated. Some of this is directed at the Department of Health in terms of the level of support provided, but much is*

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505 Neil Bateman Transcript 12 March 2021 p152 INQY1000109

506 This conclusion is fully understandable. However, so far as Peter Stevens personally is concerned the picture is more nuanced: when asked: *“Did you feel a degree of disdain or contempt as a matter of fact for some or all of the beneficiaries of the Macfarlane Trust?”*, he replied: *“From somebody who started with the Macfarlane Trust in 1987 or ‘88 when it got going and eventually left the whole infected blood operation when it was taken away from me over 30 years later, of course I didn’t.”* He was a trustee who was particularly involved in talking to beneficiaries at away days, when there were some; was generally well regarded when he was involved with the Eileen Trust; he gave his time voluntarily, and during closing questions he confirmed that it had been *“the principal occupation during my retirement.”* He had particular familial motivations for becoming involved, and few who saw his evidence are likely to forget that he became overcome when asked why he did it. Peter Stevens Transcript 24 February 2021 pp43-44, p162 INQY1000099

507 She had obtained a degree in voluntary sector management, worked in a cancer charity, and previously been a nurse. Written Statement of Elizabeth Carroll paras 4-5 WITN3078001

508 Liz Carroll said she had met Jan Barlow a couple of times, before or after a Partnership Group meeting which they both attended, and probably in relation to the Caxton Foundation. Elizabeth Carroll Transcript 5 March 2021 p149 INQY1000105. Jan Barlow, for her part, thought that one-to-one meetings with Liz Carroll were very limited, and thought that a meeting on 29 January 2015 between Roger Evans, Liz Carroll and herself was the first to have been formally arranged. Jan Barlow Transcript 3 March 2021 p155 INQY1000103. Roger Evans, for his part, had met Liz Carroll at events such as the APPG meetings, as he recalls, but he had never been in a formal meeting with her. Roger Evans Transcript 5 March 2021 p76 INQY1000105

509 The report was completed and published at the beginning of 2015. Entitled *“Inquiry into the current support for those affected by the contaminated blood scandal in the UK”*, it was critical of many aspects of the support schemes. The All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood: Inquiry into the current support for those affected by the contaminated blood scandal in the UK January 2015 RLIT0000031

*focused on the lack of respect and understanding of the issues beneficiaries face by the staff of these organisations. This was also reflected in the many personal stories relayed by the MPs who spoke at the Back Bench Debate. The Haemophilia Societies [sic] own experience backs this up, including at a recent meeting between myself and the Chief Executive, Jan Barlow and Chair of The MacFarlane Trust Roger Evans, where they expressed the opinion that the Department of Health should wait before responding to Penrose so more people will have died and they will have less to pay out.”<sup>510</sup>*

It is this last sentence which is contentious: did Jan Barlow and Roger Evans say what she recorded they had – that the Department of Health “**should wait**” for the reason given – at their “*recent meeting*” (it was on 29 January).

It is clear that neither Liz Carroll nor Jan Barlow found their meetings particularly easy and comfortable, and Jan Barlow said as much to Roger Evans.<sup>511</sup> For her part, Liz Carroll said that she and Jan Barlow “*came at things from a very different perspective, and shared little ground when it came to our approach to matters despite serving the same community.*”<sup>512</sup>

Liz Carroll recollected that the meeting of 29 January had been called at the request of the Trust, and that it was not a formal meeting: there was no agenda. Surprisingly, though the meeting was not formally minuted, no note was taken of it, nor made immediately afterwards, by any attendee. What was said at that meeting therefore relies entirely on recollection. The anticipated report of the Penrose Inquiry was amongst the matters discussed. The controversial sentence relates to this.

The contentious statement first became public when Liz Carroll sent her letter of 10 February (12 days after the meeting), to Jane Ellison, Parliamentary Under-Secretary of State for Health, with copies being sent to the APPG, shadow health ministers, the Secretary of State for Health, and two other parliamentarians.

Contrary to what is in the letter, there is in fact no evidence that Roger Evans expressed any such opinion as the letter attributed to him. Liz Carroll said in evidence to the Inquiry that **Jan Barlow** did: but she did not say that Roger Evans said anything to express agreement with what she said.<sup>513</sup>

The first written account of what had been said during the meeting came in the minutes of a meeting of the Haemophilia Society board of trustees, held on 4 February, six days after the meeting. The minute reads:

*“The possible implications of the Penrose report were then discussed and LC [Liz Carroll] stated that this will have an impact UK wide and might bring things to a*

510 Email from Liz Carroll to Trustees of the Haemophilia Society 10 February 2015 pp3-4 WITN1122041

511 Roger Evans Transcript 5 March 2021 p91 INQY1000105

512 Written Statement of Elizabeth Carroll paras 9-10 WITN3078009

513 Written Statement of Elizabeth Carroll para 17 WITN3078009, Elizabeth Carroll Transcript 5 March 2021 pp185-186 INQY1000105

*head early in to the new parliament. The Haemophilia Society would keep the pressure on whoever is in government to make an announcement as quickly as possible. Jan then expressed her opinion that the DH should wait for as long as possible before making any decision as more people will have died and there will be less people to pay and fight for payment. LC did not comment on this point.”*<sup>514</sup>

The trustees of the Society discussed this. They decided Liz Carroll should write to Jane Ellison, copied as above, stating the view that the current administration and system was not fit for purpose, and giving some examples why that was.<sup>515</sup> This led to the letter of 10 February. Nothing was minuted which called upon Liz Carroll to refer specifically to the statement said to have been made by Jan Barlow, let alone to imply that Roger Evans was complicit in it. Nonetheless, she chose to include it, and to imply that he had been. The draft letter was circulated amongst the Board. Her view now is that the Board backed her sending it as she had written it. Discussion amongst trustees followed by email, such that by 22 February Liz Carroll was able to report that the consensus was that the letter should be published on the website. That then happened, and wider publicity still was thus given to Liz Carroll’s account.

Liz Carroll not only wrote to Jane Ellison on behalf of the Society on 10 February. She also wrote on 13 February to Jan Barlow.<sup>516</sup> In this, separate, letter she said she would be writing to the Minister about “*our whole conversation, including your thoughts on possible outcomes from the Penrose Inquiry and your possible plans to ... suggest the potential of merging the 3 charities to simplify the complex system currently in place*” but said nothing about the alleged comment, nor that she had just alerted, or was just about to alert, the Minister, Secretary of State, the Shadow Secretary of State, APPG co-chairs and other MPs, to it, though proper practice would have suggested she should have done so.

The publication on the website provoked an angry call from Roger Evans. He first attempted to contact Bernard Manson, the chair of the Society with whom he understood he had a good relationship. When he was unavailable, he spoke to Liz Carroll. Her account of this call was given almost contemporaneously in an email to trustees.<sup>517</sup> She records that he was very angry, said the comment was libellous as the words had not been said, “*and if anything was said it was him recounting an anecdote.*” He threatened legal action unless the letter was retracted within 24 hours. In evidence, Roger Evans said he had no recollection of mentioning the words put in quotes above.<sup>518</sup> It remains a curiosity that he should contemplate having said something that was misunderstood, since despite the wording of the letter the evidence is clear at least on this – that Roger Evans did not say nor indicate anything to show his support for the contentious words, if indeed Jan Barlow spoke them.

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514 Emphasis added. Minutes of Haemophilia Society Board of Trustees meeting 4 February 2015 pp5-6 WITN3078010

515 Minutes of Haemophilia Society Board of Trustees meeting 4 February 2015 p6 WITN3078010

516 Letter from Liz Carroll to Jan Barlow 13 February 2015 MACF0000059\_092

517 Email from Anon to Liz Carroll 23 February 2015 HSOC0029441\_015

518 Elizabeth Carroll Transcript 5 March 2021 pp83-84 INQY1000105

What then followed were threats by the Trust to sue the Society for libel unless the statement was retracted. Under this pressure, Liz Carroll felt (she said) that the Trust should accept the unequivocal advice of their lawyers, which was to accept that Jan Barlow did not say what had been quoted and should apologise. Liz Carroll was instructed by the chair of the Society to follow that advice. A draft retraction travelled between solicitors, in the course of which the allegation was no longer referred to as being “*incorrect*” (the first draft) but ended up being described as “*false*”. The Society apologised unreservedly to the beneficiaries of the Trust; it accepted that Roger Evans, Jan Barlow and the Macfarlane Trust did not express the opinions attributed to them.<sup>519</sup>

The incident was undoubtedly public, and soured relations between the Macfarlane Trust and the Society. It further reinforced the negative views many beneficiaries had of the way in which those running the Trust regarded them. However, what actually happened at the meeting is impossible now to determine with any degree of certainty. Jan Barlow is emphatic that she did not say the words attributed to her; Liz Carroll is certain she heard what she heard.<sup>520</sup> I am inclined to accept that she believes she heard the words she now attributes to Jan Barlow: though I suspect that what is now certainty in her mind may have been developed by the way in which the comment was picked up in discussion at the Trust board.<sup>521</sup> It had not hitherto been a point of apparent central importance to Liz Carroll. Given the state of relations (cool) between the Society and the Trust prior to the meeting, and the difference of personal approach which Jan Barlow and Liz Carroll had, it is unlikely that an unguarded comment to the effect that policy should be one of saving money rather than supporting people with a just claim upon that money would have been made by Jan Barlow, in particular to the person whose job it was to represent most of the would-be claimants.<sup>522</sup> It is more likely that Liz Carroll came into the meeting with a view of the attitudes likely to be struck by Jan Barlow and Roger Evans, based upon the experiences of members of the Society as had been reported to her. Might she, in effect, have heard what (in good faith) she expected to hear, rather than what was actually being said?<sup>523</sup> Liz Carroll did not at that point

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519 Written Statement of Elizabeth Carroll paras 35-53 WITN3078009

520 Jan Barlow Transcript 3 March 2021 pp157-158 INQY1000103, Roger Evans Transcript 5 March 2021 p154, p186 INQY1000105

521 Minutes of Haemophilia Society Board of Trustees meeting 4 February 2015 WITN3078010. They do not give details of the discussion, but oral evidence to the Inquiry is to the effect that a trustee picked up on the comment which Liz Carroll reported and asked that Alastair Burt be told of it: “*it was the point where Liz Carroll said she had this meeting with Roger Evans and Jan Barlow, and she come [sic] out with a quote that she said Jan Barlow said ... I said, ‘Whoa, whoa, can you repeat that?’ She repeated that, and I said, ‘I want that put in the minutes, please, that has to go in minutes’, and it was ... Q. Your statement suggests you asked Ms Carroll to report this to Alistair Burt. A. Yes, yes. Q. And that was done. A. Yes.*” Alan Burgess Transcript 28 October 2019 pp97-100 INQY1000045

522 Where a meeting is not intended to be confrontational, then generally participants will choose their words carefully if they have any sense that others will take visceral objection to the view they might be seen as supporting.

523 It was widely the view of criminal barristers in the 1970s and 1980s in the days before the tape recording of interviews under caution that when, following interview, police officers recorded in their notebooks comments indicative of guilt, but the suspect maintained that they had not actually made such comments, or that they had been taken out of context with what else they were saying, this was attributable not so much to the dishonesty of the officer concerned (or that of the suspect) as to the police officer hearing what the officer expected to hear: people often do not listen to what is actually said, but hear what they want or expect to hear from the person talking to them.

act as a chief executive should. If the comment had been made, in the way she recounts, she should have challenged it immediately. She was, however, inexperienced. But there is nothing in her account which suggests she was so taken aback that it affected the rest of the meeting, as might be expected. Nor did it feature significantly in her account until a little while later when she ruminated upon it.<sup>524</sup> She should, then, have recognised the possibility that she might have misheard or misunderstood what was being said. The conversation was not being recorded nor minuted at the time. She should, if acting professionally, have raised the issue in either (preferably) an email or note to Jan Barlow copied to Roger Evans, to the effect “did I really hear that?” and at the very least, make some mention of it in the letter which she wrote to Jan Barlow on 13 February. This letter failed to mention the comment which she was reporting to the ministers and MPs. According to the minutes, she was not obliged to make any reference in her letter to MPs to that comment. Given the sensitivities, it would have been desirable that the Trust be contacted before the letter was made public, even if the conversation might not have been an easy one. There was no reason for assuming that because Roger Evans said nothing, he agreed with the comment attributed to Jan Barlow. Since Liz Carroll herself said nothing, the difference between her position and that of Roger Evans could only be that she assumed the position of Roger Evans was that he supported Jan Barlow, and this is a reflection of what she had heard from others rather than anything she recalls from his behaviour at the time.

A suggestion was advanced from some core participants, through Counsel to the Inquiry, that one possible reconciliation of the differing accounts is that Jan Barlow said something to the effect that the Government **would probably want** to delay to lessen their bill, rather than that was what they **should** do.<sup>525</sup> Too much depends on the word “*should*” for it to be reliable in these circumstances.

It may well be that what these core participants have suggested is what happened. However, I cannot say that that is the case: the evidence from Jan Barlow is that she said nothing that might have been mistaken. What can be said with greater certainty is that what happened was a sad and sorry episode. It caused further upset and irritation to many beneficiaries, seeming to many to justify the suspicion they had that neither Roger Evans nor Jan Barlow had their interests at heart. Liz Carroll did not act professionally. In other hands the matter would have been solved. If anything like the comment had been said it would have almost certainly then have been retracted or disavowed: if it had not, but had instead been maintained in the words Liz Carroll thinks she heard, then it both could and should have been called out – but there would then have been much more certain evidence of it. For his part, Roger Evans risked spending the funds of the Macfarlane Trust pursuing a legal action when it was not part of the charitable purposes of the Macfarlane Trust to do so, and it is not easy to see how to do so would benefit the beneficiaries, so as to come within the scope of ancillary powers sufficiently to justify the expenditure of charitable funds. Instead, the events and how they were handled added poison to an already damaged relationship.

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524 Written Statement of Elizabeth Carroll paras 17-19 WITN3078009

525 Roger Evans Transcript 5 March 2021 p188 INQY1000105

Whether or not the comment was made forms part of the whole context. The only reason this incident, and the one word “*should*”, has merited the length of discussion it has in this Report is because it had assumed a significance beyond that which it deserved. It must remain uncertain whether or not the words were spoken as reported, though the likeliest scenario is that none of the accounts I have been given is entirely accurate, and what happened owed much to the way in which the protagonists thought of each other at the time.

Following the publication of the APPG report and parliamentary debate (and the fracturing of the relationship between the Haemophilia Society and the Macfarlane Trust after the letter of 10 February), the writing was on the wall for the continuation of the Alliance House Organisations. Jan Barlow was concerned to ensure that they continued to operate. Some 15 months after the report, however, Roger Evans decided to vacate his post. During that 15 months nothing was done, as it should have been, by the Macfarlane Trust to address the concerns which the APPG had highlighted. When asked whether the Macfarlane Trust put in place any kind of programme for analysing the criticisms and working out what to do to address them, he said that he did not recall what the Trust did. He said that Jan Barlow, as chief executive, would have been commissioned with carrying out the work to address the concerns, but could give no further detail. He accepted, however, that it would have been helpful to have worked through the various criticisms and drawn up an action plan.<sup>526</sup>

Relations with the Society were at a standstill. The Trust refused to accept any nomination of a new trustee by the Society. Roger Evans lost trust in Jan Barlow: she had a lengthy absence from work due to circumstances beyond her control, but Roger Evans felt that when he wanted to talk to her there was no contact. He assumed that she was deliberately avoiding responding to him.<sup>527</sup> There is little evidence that the Trust took any steps actively to address the concerns raised by the APPG. The impression left is that it was coasting, apprehensive as to the form in which the sums available for beneficiaries would be administered in future, and without the trust between chair and chief executive which was necessary if the Trust were to take any decisive steps.

In 2016 the Department of Health had reached the view that the Alliance House Organisations should, insofar as England was concerned, be administered as one scheme. In early 2017 it determined that the administration of the schemes would be brought in-house and would

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526 Roger Evans Transcript 5 March 2021 pp71-75 INQY1000105. The minutes where the report was discussed suggest that the board itself did not specifically task her to deal with any of the criticisms: it was summed up by one trustee as “*as good as could have been expected in the circumstances*”; another thought the review flawed from the outset, that the beneficiary community had not commented on it, and the report had not recommended that the Alliance House Organisations be abolished. Minutes of Macfarlane Trust Trustees meeting 26 January 2015 p1 MACF0000022\_048

527 He speculated that she was “*colluding*” with the chair of the Caxton Foundation, Christopher Pond, whom he thought “*may well have been the architect of the covert attempted takeover by CF [Caxton Foundation], leading to my resignation.*” He added that he “*sensed*” that Jan Barlow was “*looking for a path forward with restructuring, in a way which suited her interests over those of the MFT. I lost trust in her integrity and would not have been able to defend the covert plans with the beneficiary community.*” Written Statement of Roger Evans paras 318-319 WITN3859002. No evidence of an attempted takeover has been found by the Inquiry.

be done by the NHS Business Services Authority (“NHSBSA”).<sup>528</sup> A consequence of that, and of the decision that had already been taken in Scotland to establish a Scottish scheme, was there would be four separate schemes, one for each of the four nations, health being a devolved matter.

As a charity, and being separate from the government, the Macfarlane Trust had to decide how to dispose of such assets as it maintained. At a meeting on 31 July 2017, the board decided to pursue one of four options, namely to distribute reserves (expected to be approximately £1.4 million) through a targeted, time-limited grants programme, at the end of which the Trust would be wound up. It expected to do so before the lease on the Alliance House offices expired in February 2019.<sup>529</sup> Then beneficiaries were asked at the beginning of January to apply for a grant covering the cost of works (such as installing replacement boilers) before 26 February 2018. When Jan Barlow reported to the board at the end of March 2018, it appeared that there were 74 applicants, who between them had requested just under half of the reserves.<sup>530</sup> Alasdair Murray had taken over as chair when Roger Evans left.<sup>531</sup> His evidence was that there was no time to run another programme to run down the reserves by individual application: he accepted it would have been better if the applications process had been re-worked.<sup>532</sup> There had been no discussion about it with the beneficiaries.

By November 2018, because some of the allocation for grants which had been requested had not in the event been taken up by payments, there were reserves in total of £1,321,174. The majority of these were free reserves. Two separate donations were included in these sums, the “Honeycombe Memorial Fund” and the “Wilson Empowerment Fund”. The first had some £40,000 remaining. The original donation had not been restricted to any particular purpose, but had been designated by the trustees to provide support to widows and bereaved partners without children. £27,000 of the original capital remained. The trustees decided to remove the designation, and to add the £27,000 to the free reserves.

At its meeting on 1 November 2018, the Trust recorded the decision in respect of the Honeycombe Fund, and accepted legal advice that the funds and assets could be transferred to the Terrence Higgins Trust (“THT”). This would be subject to a restriction that the funds and assets transferred to the Trust were to be spent in line with the objects of the Macfarlane Trust’s deed and scheme of amendments – that is, that the use of those funds would be restricted to supporting the purposes set out in the scheme.<sup>533</sup> In practice, this means that the scheme administrator (THT) is obliged to deal with the funds for the same beneficiary cohort, under the same principles as applied when the Macfarlane Trust was the scheme

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528 Department of Health *Infected blood: Government Response to Consultation on Reform of Financial and Other Support* 13 July 2016 p18 WITN3953052, Alasdair Murray Transcript 9 March 2021 pp138-139 INQY1000106

529 Minutes of Macfarlane Trust meeting 31 July 2017 pp1-2 MACF0000027\_107

530 Minutes of Macfarlane Trust board of Trustees meeting 26 March 2018 p1 MACF0000028\_019

531 No reason for his abrupt departure was given contemporaneously. However, see footnote 527.

532 Alasdair Murray Transcript 9 March 2021 pp149-150 INQY1000106

533 Minutes of Macfarlane Trust meeting 1 November 2018 pp3-4 MACF0000028\_056

administrator.<sup>534</sup> It did – and does – not give the THT freedom to use the money in support of those who are infected with HIV but would not have qualified as Macfarlane beneficiaries.

The souring of relations between many of the beneficiaries and the trustees was well known. It had arisen in large part because of the way in which the Trust had discharged its duties, in particular by its exclusion of beneficiaries both from involvement in policy, and from information about process. It is a pity that lessons had not been learned from this history such that beneficiaries were consulted meaningfully about the transfer of administration to the NHSBSA, and of reserves to THT. There was ample time to do so once the transfer of the schemes to the NHSBSA was announced in March 2017. This is probably because the trustees expected that their invitation for beneficiaries to apply for single grants from the remaining funds would exhaust the available funds. It might however have been foreseen that the funds would not all be used up in this way, and decisions would need to be taken as to what should happen if they did not. Had there been consultation, beneficiaries would have had the chance to raise the concerns which have subsequently been expressed. It may well be that after consultation and the further consideration to which that would have given rise that a different decision might have been reached. That opportunity was lost.

A consequence for many has been a perpetuated sense of grievance. What remains of the former Macfarlane Trust assets are now in the hands of the THT. These assets remain subject to the obligation upon the THT to administer them for the benefit solely of those who would have qualified from the Macfarlane Trust deed.

## Commentary

The facts and evidence set out above speak for themselves. They tell a sorry tale of a payment scheme which had significant problems from the very start both in the way it was set up, and the ways in which it operated. The failings are obvious. They are failings of the State, the Trust (in so far as it can be seen as a body), and of individuals concerned in its management when they acted in ways they should not have done, or more usually failed to act when they should.<sup>535</sup>

Nonetheless, lest there be any doubt that I take the view that in these respects there were serious failings, they merit summarising here in a number of bullet points.

The worst aspect of this history, however, is its effect on the people who needed to be supported properly and were not. People whose suffering was supposed to be alleviated by the payment scheme instead had that suffering exacerbated: they felt kicked, and kicked again, when they were already down. They were repeatedly rebuffed in their attempts to argue that they deserved more and better from authority.

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534 Written Statements of Ian Green para 4, para 8 WITN3075020, Minutes of Terrence Higgins Trust Board of Trustees meeting 26 November 2018 WITN3075027

535 It should be remembered, however, that the trustees were giving their own personal time freely in order to serve others. For some, this involved significant sacrifices of their personal time. It should also be acknowledged that there were trustees and staff members who were committed to doing the best they could within the limitations imposed upon them.



The way in which the Government responded to the infection of people with HIV by establishing this Trust, operated as it was in the ways described, added layers of suffering – psychological, economic, and social – to an already devastating disease.

The list which follows cannot do full justice to what happened – for which reference should be made to the text, and (for those who have time and inclination) to the underlying documents that support it. However, in brief:

- (1) The Trust should not have been set up as it was:
  - as a charity, redolent of the begging bowl
  - without any assessment of actual financial needs
  - with no guarantees of, or plan for future funding, leading to insecurities about funding
  - with inadequate resources, both of money and of staffing
  - too small to function as well it might<sup>536</sup>

In the light of the findings in previous chapters, it can also be said that the Government wrongly took the approach that the sole entitlement of any beneficiary should be to ex gratia payments, rather than a correct approach which would have been compensatory, but I want to make it clear that the conclusions of this chapter summarised here stand alone and apart from that. The wrongs reported in this chapter stand independent from (though additional to) that issue.

Many of the issues related to providing for the needs of beneficiaries were exacerbated by the trustees holding a reserve, which they were effectively obliged to do if they were not to rob the tomorrow of some beneficiaries to pay for the today of others. Thus, government having set the Trust up, with a low level of funds if looked at per capita, it should not have left it with no guarantees of, or plan for future funding, leading to insecurities about funding and an inability on the part of the Trust to develop coherent and sustainable policies aimed at reducing suffering. It took far too long (2002) for government to accept that the Trust would benefit from (indeed, needed) regular annual funding. Thus a reserve had to be built up. The Department of Health then used the existence of the reserve to justify withholding additional sums which were otherwise appropriate to meet the continuing needs of beneficiaries, at a time when (again) there were uncertainties of funding continuing.

- (2) The Trust should not have been run as it was:
  - The Trust felt itself subordinate to the Government when it should not have been, and as a result did not campaign when campaigning might have been productive. It was too keen to accommodate what it thought the Government would wish (though this is more its fault than it is that of the Government).

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536 This was exacerbated when the other Alliance House Organisations were set up as separate organisations, albeit linked by disease transmitted by treatment with tissue, blood or blood products.

- A climate of anxiety, fear and distrust was created, recognised by at least some chief executives and chairs, and left unaddressed.
- The decision to have “office guidelines” which were not to be published to beneficiaries was, quite simply, wrong. Roger Evans could see no good reason for it (and he was right); the reasons Peter Stevens gave for it amount to an irrational fear that beneficiaries would seek to take unfair advantage of the Trust, for which there is no objective evidence amongst the beneficiaries of the Trust.
- A consequence was unfairness, added distress and anxiety. Applications were deterred, when it was proper for them to have been made, because applying to the Trust was not only seen as bureaucratic but also as demeaning, intrusive, demotivating and embittering.

Furthermore:

- decisions were delayed, though needs were urgent;<sup>537</sup>
- the way in which the Trust dealt with some applications made in respect of needs is epitomised by its handling up to 2005 of the issue of assistance for those of its beneficiaries who sought to have a baby as safely as was possible. Though there may be some sympathy for a Trust with limited resources trying to meet all the anticipated calls upon it needing to balance expenditure on a claim of one nature against a claim of another kind, the Trust could and should have dealt with this issue better: promptly, decisively, keeping in mind the human suffering at its heart. The account set out in the text justifies the comments made about it in oral evidence.<sup>538</sup> The fact that it was debated whether the Trust should support assisted conception at all, because it would lead to another beneficiary to be supported, will have astonished readers, and invited indignation. The delays, for a couple seeking to conceive would have been far too long even if the husband had not been living on borrowed time. It amounted to procrastination without regard for the deep seated human desire which was at its heart: it lacked humanity;
- the application process for grants:
  - was time-taking and bureaucratic;
  - had to have support in most cases from the treating clinician;
  - might involve giving details of household income and expenditure (despite the fact that many of the details had already been provided);
  - might involve being visited at home or photographs being taken of the quality of the home in order to show it was sufficiently poor;

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537 See footnote 257 for a discussion of the psychological harm of delays.

538 Amanda Beesley Transcript 16 October 2019 p137 INQY1000042, quoted above.

- required it to be shown that other sources of support and funding were not available;
- the Trust started to require applicants for grants to show “exceptional circumstances” without applicants having any clear idea of what they could be, and how they were defined;
- the criteria and process for appealing the refusal of a grant was unclear and poorly understood; it may not even have been recognised by an applicant that there was that possibility;
- the Trust was found weak in monitoring and evaluation, without which it would be unable to answer whether it was helping those in greatest need, yet appears to have done nothing to rectify this;
- the Trust did not sufficiently ensure any effective way in which the views of beneficiaries could be fed back to trustees.

In addition:

- the leadership of the Trust between 2012 and 2016 lacked the vigour it should have had in pursuing better funding, and was less observant of its duty to serve the interests of its beneficiaries;
- beneficiaries were treated by some trustees, and by Martin Harvey as CEO, in an apparently uncaring, dismissive, disparaging and disdainful manner;
- Peter Stevens spoke (with Martin Harvey) and wrote internally in unacceptable and disdainful terms about some beneficiaries;
- Roger Evans when chair recognised that aspects of the system were “*humiliating and intrusive*”, causing unhappiness amongst beneficiaries, and “*the whole thing was not the right way to go about it*”:<sup>539</sup> allowing that to be the case was wrong, but what was worse was that when it was realised that this was the case little or nothing was done by the Trust to rectify it;
- when a survey of beneficiaries was reported to the trustees in 2013, identifying sources of dissatisfaction, Jan Barlow was asked to take steps to action its recommendations but did not;
- the Trust received a report from the APPG in 2015 identifying failings and did little or nothing in response;
- relations between the trustees became very difficult such that the board did not function as it should have done: this was largely the fault of Roger Evans;
- when the Trust was superseded by the England Infected Blood Support Scheme, Welsh Infected Blood Support Scheme, Scotland Infected Blood Support Scheme and Northern Ireland Infected Blood Payment Scheme, the process of disbursing

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539 Roger Evans Transcript 4 March 2021 p170, pp174-175 INQY1000104

its reserves (including the Honeycombe monies) should have been determined in consultation with the beneficiaries, in a way which best ensured the funds were distributed fairly and contemporaneously amongst beneficiaries.

## 6.4 Government Response to HIV Infections through Blood or Tissue Transfer

This chapter describes the initial Government position that financial support for those infected with HIV should not be extended beyond people with haemophilia to people infected with HIV through blood or tissue transfer. It charts campaigning by some members of Parliament and the media to overcome this position.

### Key Dates

**November 1987** the Government announces a grant of £10 million to the Haemophilia Society to enable the Society to establish a special fund for people with haemophilia infected with HIV; does not include people infected through blood or tissue transfer.

**July 1988** civil servants advise ministers against introducing a scheme for people infected with HIV through blood or tissue transfer.

**December 1990** the Government agrees to settle HIV litigation for people with haemophilia; people infected through blood or tissue transfer are excluded.

**February 1991** civil servants advise a line to take against payments for people infected through blood or tissue transfer.

**April 1991** the Secretary of State agrees to “*hold the line on these cases*”.

**May 1991** *The Observer* launches a campaign to “*win compensation for the forgotten NHS victims of AIDS*”.

**December 1991** the Secretary of State writes to the Treasury proposing financial support for people infected through blood or tissue transfer.

**February 1992** Government announces extension of financial support to people infected with HIV as a result of blood transfusion or tissue transfer.

### People

**Robin Cook MP** advocated providing financial support to people infected with HIV through blood or tissue transfer

**Strachan Heppell** senior civil servant, Department of Health

**John Marshall MP** advocated providing financial support to people infected with HIV through blood or tissue transfer

**David Mellor** Chief Secretary to the Treasury

**William Waldegrave** Secretary of State for Health

### Abbreviations

**H(A)** Sub-Committee on AIDS of the Cabinet Home and Social Affairs Committee

This chapter considers the Government’s response to the question of whether to make payments to individuals infected with HIV by blood transfusion or tissue transfer.<sup>540</sup>

It begins in late 1987, though much of the relevant evidence concerns the period from late 1990 to early 1992, when the Government decided to make such payments. The operation of the trust which ultimately resulted from this decision, the Eileen Trust, is discussed in the following chapter.

## 1987-1988: early consideration

On 10 November 1987, the Sub-Committee on AIDS of the Cabinet Home and Social Affairs Committee (abbreviated as “H(A)”) agreed to make £10 million available to people with haemophilia infected with HIV by blood products.<sup>541</sup> However, the Sub-Committee decided against including people infected by blood transfusion and transplants in this payment scheme. Its decision included several strands of reasoning that were to feature in discussions of this issue over subsequent years: in particular, attempts to distinguish people with haemophilia from others who had been infected by HIV, and an emphasis on the importance of ring-fencing payments to haemophilia patients.<sup>542</sup> It was explicitly recognised that certain other groups “*had a very strong claim to be included in the scheme*”<sup>543</sup> but the Sub-Committee agreed that “*the primary consideration should be that the scheme should be tightly ring-fenced.*” It was decided that there should be further consideration, undertaken very quickly, by the Secretary of State or Health and Social Services (John Moore) in consultation with the Chief Secretary to the Treasury (John Major) as to whether, if the proposed scheme were to be extended to other groups, it could be ring-fenced to them alone,

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540 The remainder of this chapter generally refers to transfusion patients rather than also to those infected by tissue transfer. It does so both as a shorthand for the wider group and to reflect how most of the contemporaneous documents were written. The payment scheme which was eventually created covered infection by both of these routes.

541 Minutes of Home and Social Affairs Committee Sub-Committee on AIDS meeting 10 November 1987 p10 CABO0100016\_011. Memo on Special Financial Assistance for Haemophiliacs from the Secretary of State for Social Services 4 November 1987 p5 CABO0100001\_002

542 The meeting minutes record the following: “*It was estimated that about 10-20 non-haemophiliacs had been infected by HIV as a result of blood transfusions and other transplants. There was a strong case in fairness for extending the scope of the proposed scheme to cover these people and also, perhaps, those who had otherwise been infected by HIV in the course of their medical treatment. On the other hand, such persons did not suffer from the full range of disadvantages of haemophiliacs with the HIV virus; in particular, they did not have a pre-existing medical condition which made it difficult for them to obtain insurance at normal rates to secure provision for their families. It was vital that the proposed scheme should be very tightly ring-fenced, and it would be more difficult to achieve this if the scope of the scheme were to be widened beyond haemophiliacs. Widening the scheme might also mean that the Haemophilia Society would not be suitable to administer it.*” Minutes of Home and Social Affairs Committee Sub-Committee on AIDS meeting 10 November 1987 p9 CABO0100016\_011

543 A memorandum prepared for the Lord President of the Council, William Whitelaw, who chaired the Sub-Committee, also recognised that “*Certain other AIDS victims (eg. non-haemophiliacs infected through blood transfusion ...) would seem to have an equally strong case for special assistance.*” Memo from Anthony Langdon to the Lord President 6 November 1987 p3 CABO0000205. Emphasis in the original.

but that unless the Secretary of State and Chief Secretary were so satisfied, the scheme should be introduced, as proposed by John Moore, for people with haemophilia only.<sup>544</sup>

The precise extent of the further consideration which was undertaken is unclear. By 11 November the Secretary of State had decided not to extend the proposed arrangements to cover other groups.<sup>545</sup> Malcolm Harris, writing in June 1988, suggested that “*Following the meeting of H(A) which discussed the haemophilia case in November, we gave thought to their view that non-haemophiliacs should be included provided that the ring fencing arrangements, which they regarded as ‘clearly vital’ were not weakened. It was our view at that time that the haemophilia ring-fence was not particularly robust and thus advised that it should not be weakened further by the inclusion of other groups.*”<sup>546</sup>

On 12 November 1987 the Secretary of State reported to the Cabinet that he had completed the consultations that H(A) had invited him to carry out with the Chief Secretary to the Treasury, and that it was proposed to announce the financial assistance for people with haemophilia the following week.<sup>547</sup>

On 16 November 1987, the Minister of State for Health, Tony Newton, announced the decision to make a £10 million ex gratia payment to enable the Haemophilia Society to establish a special trust to provide financial help to people with haemophilia infected with HIV and their families.<sup>548</sup> Transfusion recipients who had been infected with HIV were not included.

Limited further consideration was given to a scheme for transfusion patients the following year. In February 1988 it was noted that a number of MPs had written seeking special financial payments for those infected with HIV by blood transfusions in line with the ex gratia payments for people with haemophilia. The suggested line to take was that “*After careful consideration*” the Department of Health and Social Security (“DHSS”) concluded that the combination of circumstances applicable to those with haemophilia “*does not apply to those who unfortunately have become infected with HIV through blood transfusion.*”<sup>549</sup>

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544 The Lord President wrote to the Prime Minister on 11 November 1987 informing her of the Sub-Committee’s decision. His minute noted that the Secretary of State had been asked “*to give some thought to the feasibility of adjusting his proposed definition of eligibility so as to include the few known cases of non-haemophiliacs infected with the AIDS virus by NHS treatment. Some members of H(A) wished to see these cases included, if that could be done without weakening the ring-fencing of the arrangements, which is clearly vital.*” Letter from the Lord President to the Prime Minister 11 November 1987 p1 DHSC0002375\_032

545 Memo from Michael Lillywhite to Flora Goldhill 11 November 1987 p2 DHSC0002375\_050. See also Written Statement of Michael Lillywhite para 3.17 WITN7087001

546 Letter from Malcolm Harris to Strachan Heppell 15 June 1988 p2 DHSC0003960\_012. Malcolm Harris was an Assistant Secretary in HS1.

547 Minutes of Cabinet Office meeting 12 November 1987 p5 CABO0000185

548 Hansard parliamentary debate on Haemophiliacs (Financial Assistance) 16 November 1987 p1 LDOW0000241

549 Namely that “*their employment prospects and insurance status were already affected by their blood disorder, and the hereditary nature of haemophilia can mean that more than one member of the same family may be affected.*” Memo from Dr Roger Moore to A Smith 22 February 1988 p2 DHSC0002845\_013

On 16 May 1988 the Secretary of State met Robin Cook MP, who had been advocating some form of financial assistance for transfusion recipients, to discuss the issue: a background brief prepared for the Secretary of State recommended that he maintain the existing line to take.<sup>550</sup> Nevertheless, following this meeting, the Secretary of State asked officials to consider how financial help could be provided to recipients of HIV infected blood and organs.<sup>551</sup> A 25 July 1988 minute for the Minister of State for Health recorded that officials had worked up a scheme of financial help for blood transfusion and organ/tissue recipients with AIDS on the lines indicated by Ministers.<sup>552</sup> However, the author of the minute, Strachan Heppell, advised against introducing such a scheme, “*although that may seem a harsh view to take*”, for three main reasons: it could not be ring-fenced as the haemophilia scheme had been; reaching fair decisions would be “*extremely difficult*” (especially if extended to those who may have been infected overseas); and “*the wider we extend help for those with HIV infection, the more we raise the general issue of compensation for NHS linked infection.*”<sup>553</sup>

That same day, 25 July 1988, John Moore ceased to be Secretary of State for Health. The DHSS was split into two separate departments: Kenneth Clarke took over as Secretary of State for Health, and John Moore became Secretary of State for Social Security. By 28 July 1988 the decision had been taken not to make any ex gratia payments to transfusion recipients infected with HIV.<sup>554</sup>

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- 550 Memo from Dr Moore to Mr D’Souza 11 May 1988 p5 DHSC0003960\_019
- 551 Memo from Malcolm Harris to Strachan Heppell and others 27 June 1988 p1 DHSC0003960\_015, see also Memo from Strachan Heppell to John Cashman 10 June 1988 DHSC0003960\_011. The recollection of Dr Moore was that whilst officials advised maintaining the line that there should be no such assistance, the Secretary of State wanted there to be further consideration of this issue: he thought this was partly because of the stature of Robin Cook. Dr Roger Moore Transcript 18 January 2022 pp106-108 INQY1000172
- 552 Memo from Strachan Heppell to Jenny Harper 25 July 1988 DHSC0003960\_005. An outline of the scheme was set out in a minute from Dr Roger Moore dated 21 July 1988. The numbers likely to be involved were thought to be small. At present the DHSS was aware of 12 people who had contracted AIDS from blood transfusions in the UK and fewer than 10 from organ/tissue transplants. The majority had died. The DHSS was aware of around 40 people who were HIV positive following a UK blood transfusion. Memo from Dr Moore to Malcolm Harris and others 21 July 1988 DHSC0003960\_006
- 553 Strachan Heppell was head of the Health and Personal Social Services Group within the DHSS. He wrote that “*if we included those with HIV, as we did with haemophiliacs, how do we exclude other innocent victims like the babies of infected mothers or infected health care workers? Recalling the tenor of previous discussion at H(A) we shall find it very difficult to convince the Treasury and H(A) that we are not on a slippery slope.*” Memo from Strachan Heppell to Jenny Harper 25 July 1988 p1 DHSC0003960\_005. It is clear that John Moore’s thinking was strongly opposed by officials: see Memo from Malcolm Harris to Strachan Heppell 15 June 1988 DHSC0003960\_012, Memo from Strachan Heppell to Jenny Harper 29 June 1988 DHSC0003960\_014. Dr Hilary Pickles also expressed opposition to the extension of help for transfusion patients in a 20 July 1988 minute to the Chief Medical Officer. Letter from Dr Hilary Pickles to Dr Lewis 20 July 1988 DHSC0003960\_009
- 554 A minute from Dr Roger Moore to the Secretary of State dated 28 July 1988 referred to meetings between John Moore and Robin Cook, but indicated that officials had been “*unable to avoid the logical inconsistencies inherent in helping this group whilst not extending it to other categories of HIV patients.*” Officials considered it would be very difficult to ring-fence such a scheme. Memo from Dr Moore to John Cashman and others 28 July 1988 DHSC0002842\_001, Parliamentary answer from Kenneth Clarke to Robin Cook DHSC0002842\_002. See further the oral evidence of Dr Roger Moore: Transcript 18 January 2022 pp112-3 INQY1000172



The focus within Government then shifted to the HIV haemophilia litigation and any active consideration of financial support for transfusion patients infected with HIV appears to have receded for the next 18 months or so.

## HIV litigation settlement

On 2 November 1990, William Waldegrave (later Lord Waldegrave) was appointed Secretary of State for Health. Briefing material prepared for him soon afterwards highlighted the link between the HIV litigation and possible payments to transfusion recipients. It was suggested that, if liability against the Department of Health/NHS were established or implied, there would be *“Immediate knock-on effects for those infected ... with HIV through blood transfusion (up to 120 cases including transplants)”*.<sup>555</sup>

By December 1990, and as discussed in more detail elsewhere in this Report, the HIV litigation had progressed towards settlement. On 11 December 1990, the Prime Minister announced that agreement to settle had been reached in principle.<sup>556</sup> In his written evidence to the Inquiry, Lord Waldegrave commented that, looking at the papers now, one effect of the December 1990 announcement was *“to emphasise by contrast the case of those infected by blood transfusion.”*<sup>557</sup>

This observation is supported by an 18 December 1990 letter to William Waldegrave from a lawyer acting on behalf of infected transfusion patients in Scotland, suggesting that the *“only adequate and reasonable solution”* to their infection was a *“settlement such as has been offered to the haemophiliacs who are unfortunately also infected.”*<sup>558</sup> Similarly, an 8 January 1991 letter from John Marshall MP drew attention to *“the plight of the 200 or so NHS patients (other than haemophiliacs) who contracted Aids as a result of receiving infected blood”* before commenting: *“To argue that we are compensating haemophiliacs because their illness is hereditary but will not compensate others is bad morality, poor logic and bad politics.”*<sup>559</sup> Within the Department of Health, it was noted that *“Pressure is mounting for something to be done for HIV infected blood transfusion recipients”*.<sup>560</sup> Robin Cook, writing to the Secretary of State on 31 January 1991, expressed the view that the purported distinction was *“wholly untenable ... I could understand, although not accept, this distinction, if the group to whom liability was being denied was the larger group with a larger*

555 HIV Haemophiliac Litigation: Key Facts 1 January 1991 p2 DHSC0046962\_182, Memo from John Canavan to Charles Dobson and others 6 November 1990 DHSC0004365\_008. The knock-on effects were also said to apply to those infected with hepatitis through blood products and blood transfusion, whose number was *“not known”*. HIV Haemophiliac Litigation: Key Facts 1 January 1991 p2 DHSC0046962\_182

556 Hansard extract oral answer DHSC0003654\_003

557 Written Statement of Lord William Waldegrave para 4.108 WITN5288001

558 Letter from Brian Donald to William Waldegrave 18 December 1990 DHSC0003657\_119. The author noted that his clients included a five-year-old boy and an eighteen-year-old girl, and referred to the *“vital and desperate nature of the situation”* faced by them.

559 Letter from John Marshall to Sydney Chapman 8 January 1991 DHSC0042272\_145. The letter, written in the context of an upcoming debate on a no-fault compensation bill, was addressed to a Government Whip (Sydney Chapman) and copied to the Secretary of State.

560 Memo from Charles Dobson to Philip Chinque 29 January 1991 DHSC0002431\_013

*cost, but the continued refusal to accept responsibility in this case is all the more difficult to comprehend as the numbers involved are so few and the cost of settlement would be so much less than the amount already provided for the greater number of haemophiliacs.”<sup>561</sup>*

## Early 1991: refusal to extend payments

Following John Marshall’s letter, Department of Health officials prepared a background briefing and line to take for the Secretary of State. This set out the number of reported cases of HIV infection by transfusion and described the reasoning for distinguishing between haemophilia and transfusion patients in the following way:

- “3. *The payments to haemophiliacs have recognised their wholly exceptional circumstances, whereby they were doubly disadvantaged by their pre-existing haemophilia as well as the HIV infection.*
4. *We have accepted from the outset the need to ‘ring fence’ haemophiliacs because of their special circumstances. People infected with HIV as a result of blood transfusion/transplants are no different in principle from other groups of patients harmed as an unfortunate side result of NHS treatment. For example, there are cases which fall into the category of those who acquired HIV through skin grafts or organ transplants.*
5. *Any special treatment for HIV infected blood transfusion recipients would repercuss by exciting expectations which could be difficult to contain in other groups of patients harmed as an unintended by product of NHS treatment. The direct cost of conceding for UK transfused cases with AIDS would be around £1 million and if all HIV cases are included the cost could be around £5 million. The more exceptions that are made, the closer we move to ‘no fault compensation’ without discussing the rationale, and the greater the number of claims that would result from those who feel that they too are deserving.”<sup>562</sup>*

The proposed “line to take” was: *“Payments for haemophiliacs recognised their unique combination of circumstances. These do not apply to blood transfusion recipients.”<sup>563</sup>* This position was maintained publicly until 17 February 1992.

561 Letter from Robin Cook to William Waldegrave 31 January 1991 p1 DHSC0002850\_004. The Secretary of State’s response of 7 March 1991 confirmed that the Government had no plans to extend the special financial help for haemophiliacs to those infected through blood transfusions. Letter from William Waldegrave to Robin Cook 7 March 1991 DHSC0003560\_032

562 Background brief and line to take on Blood Transfusions and HIV Infection 1990 DHSC0042272\_143, Memo from John Canavan to Stephen Alcock 14 January 1991 DHSC0042272\_142. Part of the context to the view that there should be no precedent was there was contemporaneous concern about a Bill before Parliament, taken up in particular by Rosie Barnes MP, entitled the National Health Service (Compensation) Bill which if passed would provide compensation for injuries suffered during NHS treatment without needing to show negligence on the part of the Health Service. See the evidence of Baroness Bottomley: *“We saw, understood and genuinely sympathised with the argument that those infected through blood transfusions should be treated the same as haemophiliacs infected through blood products. But at this stage, our judgement was that those arguments were outweighed by the need to protect against falling into a no-fault compensation system to which the Government was firmly opposed.”* Written Statement of Baroness Virginia Bottomley para 4.130 WITN5289001

563 Background brief and line to take on Blood Transfusions and HIV Infection 1990 DHSC0042272\_143

Negotiations over the terms of the HIV litigation settlement continued in the first few months of 1991. In evidence to the Inquiry, Lord Waldegrave suggested that there would have been very little prospect of widening the settlement to include transfusion patients.<sup>564</sup>

On 22 April 1991, as the negotiations neared their conclusion, the Secretary of State asked for a detailed note on the position of non-haemophilia patients who had been infected with HIV.<sup>565</sup> This was provided the following day, with an expanded “line to take”. The note argued strongly against expanding financial support to transfusion patients. It was said that people with haemophilia could be distinguished on the grounds that they were “*doubly disadvantaged by the pre-existing haemophilia, which affected their employment, mortgage and insurance prospects, and by their HIV infection*” and the “*hereditary nature of haemophilia can mean that more than one member of the family might be affected.*” The note further argued that “*Any extension of compensation beyond haemophiliacs could result in the piecemeal introduction of general no fault compensation*”. A covering note added that the Treasury “*would strongly resist any further concession, and might well accuse us of bad faith in even considering it.*”<sup>566</sup>

At this stage, the Secretary of State accepted his officials’ advice. A response from his Private Office recorded his agreement “*that we need to hold the line on these cases. He has added that we must emphasise the more complex history of what caused these tragic cases and say that the NHS cannot be pushed into taking general responsibility for cases like this.*”<sup>567</sup>

Meanwhile, in May 1991, a campaign was launched by *The Observer* to “*win compensation for the forgotten NHS victims of AIDS*”.<sup>568</sup> *The Times* reported that a group of patients had joined an action group, with a Merseyside solicitor involved in the HIV litigation, Graham Ross, commenting: “*The government has compensated the haemophiliacs as an act of compassion. I cannot see why that well of compassion should suddenly run dry for transfusion patients whose tragedies are equally real.*”<sup>569</sup> The issue was taken up in Parliament by MPs “*across the political spectrum. Nearly 100 have now signed an Early Day Motion calling on Health Secretary William Waldegrave to reverse his department’s ‘callous and illogical’*

564 Written Statement of Lord William Waldegrave para 4.116 WITN5288001, Lord William Waldegrave Transcript 5 July 2022 pp146-178 INQY1000220

565 Memo from Stephen Alcock to Charles Dobson 22 April 1991 DHSC0003662\_080

566 Memo from Charles Dobson to Stephen Alcock 23 April 1991 p1, p7, p9, DHSC0003560\_051. Other points made in the note included that the validation of claims for infected transfusion patients would not be as straightforward as for people with haemophilia, and that any payments to transfusion patients could result in many of those transfused since 1978 wanting to be tested for HIV, which “*would put intolerable strain on the counselling and HIV testing services of the UKBTS.*” A briefing note was also prepared for the Prime Minister on 24 April 1991, making similar points regarding people with haemophilia and the risk of moving towards no-fault compensation. Briefing for the Prime Minister 24 April 1991 DHSC0020822\_051, Letter from David Burrage to Charles Dobson 24 April 1991 DHSC0003560\_046

567 Memo from Stephen Alcock to Charles Dobson 25 April 1991 DHSC0002433\_058. A 29 April 1991 response on behalf of the Chief Medical Officer (“CMO”) noted that he “*would be concerned with ‘spread’ to hepatitis cases of various sorts.*” Memo from Jane Verity to Charles Dobson 29 April 1991 DHSC0002862\_006

568 *The Observer This little baby was killed by the NHS* 26 May 1991 ARCH0002829\_005

569 *The Times HIV transfusion victims launch payment claim* 11 May 1991 DHSC0006473\_028

*refusal to compensate the non-haemophiliac NHS victims.”<sup>570</sup> The Observer commented that the delay in agreeing to provide payments to people with haemophilia had meant that many had died before they or their families received anything: “It will be deplorable if the same curmudgeonly and legalistic approach is adopted towards this very much smaller group”. If, the newspaper added, ministers “wish to project the image of a caring National Health Service, they must face up to the consequences of past mistakes. No amount of money can erase the suffering of these NHS victims of AIDS. But it will be a disgrace if they are forced to appeal to the courts before they can secure justice.”<sup>571</sup>*

In written evidence to the Inquiry, Lord Waldegrave acknowledged that the Department knew that there were forceful arguments that transfusion patients should be treated in the same way as haemophiliacs. He added, however, that *“having succeeded in winning the argument over settlement of that [ie the HIV] litigation, including gaining permission from the Treasury in the face of very considerable concern about setting a precedent for no fault compensation, there was little real alternative in practice other than, initially, to try to hold the line.”<sup>572</sup>*

The Government continued to give some consideration to the position of infected transfusion patients over subsequent months. For example, on 31 May 1991 the Secretary of State was provided with a note on the subject for discussions with colleagues.<sup>573</sup> This set out pros and cons of extending payments to transfusion patients. The advantages included that doing so would relieve *“the political and media pressure at present on the Government”*, would reduce the risk of *“another round of embarrassing and costly litigation and criticism for ‘forcing’ people with a fatal infection to take this course”*, and that the numbers and costs involved would be relatively small if the *“concession”* could be ring-fenced. The disadvantages focused on difficulties around maintaining a ring-fence and, if it could not be maintained, the resultant pressure to compensate other categories of patient (including people with haemophilia infected with hepatitis).<sup>574</sup> The note went on to outline possible options for a payment scheme, before concluding as follows:

*“The ring-fence round the haemophiliacs is difficult to maintain. Finding another place to re-establish it is also difficult. If there is to be further movement then it might be possible to defend a ring-fence around all HIV cases infected in the UK by blood, organ and tissue donation undertaken as part of medical treatment. This further concession however would send the wrong signals to other groups already lining up to press their own case for compensation. Re-opening the no fault compensation issue would not resolve the immediate problem and could be*

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570 The Observer *This little baby was killed by the NHS* 26 May 1991 ARCH0002829\_005

571 The Observer *Illogical, indefensible, unjust* 26 May 1991 HSOC0001454

572 Written Statement of Lord William Waldegrave para 4.115 WITN5288001

573 Memo from John Canavan to Paul Ahearn 31 May 1991 DHSC0002913\_008, Compensation for Blood Transfusion Recipients with HIV SCGV0000237\_194

574 Compensation for Blood Transfusion Recipients with HIV pp2-3 SCGV0000237\_194

*unattractive on other grounds. It comes down to a question of where Ministers wish to take a stand against a claim for compensation.”<sup>575</sup>*

A handwritten note from John Canavan on the minute of 31 May described the Secretary of State as “*very twitchy ... I think I’ll open a book on the date of the cave-in.*”<sup>576</sup>

However, as reflected in the Secretary of State’s answer to a parliamentary question, in mid 1991 the Government’s position remained that it would not extend the payments given to people with haemophilia to transfusion patients.<sup>577</sup>

## Late 1991: change at the Department of Health

By November 1991, the Secretary of State’s view had changed.<sup>578</sup> He set out his position in a 2 December 1991 letter to the Chief Secretary to the Treasury, David Mellor. This noted that the Secretary of State and the Chief Secretary had discussed, at a recent Cabinet meeting, the “*continuing campaign on behalf of non-haemophiliac patients infected by HIV in the course of treatment – blood transfusion, transplant or tissue transfer – in this country.*” The letter suggested that, if the Government continued “*to refuse any help there is a real prospect that the campaign will gather pace and become a damaging and running sore over the next few months.*” It proposed that the Government should move to resolve the matter by “*recognising the needs of these people and their families in the same way as we have recognised those of haemophiliacs.*” This approach had an estimated cost of £12 million. The Secretary of State suggested that the Department pay a third of this amount, that the other Health Departments – ie those for Northern Ireland, Wales and Scotland – make a contribution in respect of cases arising in their countries and that the Treasury meet the balance from the Reserve. The letter was copied to the Ministers responsible for Northern Ireland, Wales and Scotland.<sup>579</sup>

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575 Compensation for Blood Transfusion Recipients with HIV p6 SCGV0000237\_194

576 Memo from John Canavan to Paul Ahearn 31 May 1991 DHSC0002913\_008

577 Excerpt of parliamentary questions and written answers 18 June 1991 HSOC0001432. See also Letter from William Waldegrave to S Edwards 28 May 1991 DHSC0002863\_005. An August 1991 ministerial submission, concerning correspondence with Scottish solicitors and issues relating to donor anonymity, also records that the Government position on extending financial help had not yet changed. Memo from Helen Bloomfield to Stephen Alcock 19 August 1991 DHSC0046973\_035, Memo from John Canavan to Yvonne Baxter 13 August 1991 DHSC0003641\_004

578 This can be seen in two minutes from Strachan Heppell to the Secretary of State of 28 and 29 November 1991. Memo from Strachan Heppell to Colin Phillips 28 November 1991 DHSC0002894\_011, Memo from Strachan Heppell to Colin Phillips 29 November 1991 DHSC0002537\_262. These and other documents – such as 29 November 1991 minutes from Peter Kendall to Joan Firth and from Joan Firth to Strachan Heppell – reflect misgivings amongst a number of Department of Health officials about this change in position. Memo from Peter Kendall to Joan Firth 29 November 1991 DHSC0002894\_001, Memo from Joan Firth to Strachan Heppell 29 November 1991 DHSC0002894\_002

579 Letter from William Waldegrave to David Mellor 2 December 1991 DHSC0002921\_009. The Secretary of State for Scotland, Ian Lang, responded to support a change in the Government’s position on 17 December 1991. David Hunt adopted the same position on behalf of the Welsh Office 2 January 1992 letter. Both letters proposed that the Scottish Office and Welsh Office make some payment towards the cost of the scheme, alongside a contribution from the Treasury Reserve. Letter from Ian Lang to David Mellor 17 December 1991 SCGV0000237\_072, Letter from David Hunt to David Mellor 2 January 1992 DHSC0002717\_014

Also on 2 December 1991, the most senior official at the Department of Health, the Permanent Secretary, wrote to the Secretary of State to support the misgivings about the proposed change of policy that had been expressed by Strachan Heppell. He commented that, “*unless Government is prepared to draw a line and stick to it, it will end up with a de facto (very expensive) no-fault compensation system.*” The Permanent Secretary added that the “*ringfence around the haemophiliacs is bound to be attacked, but we are unlikely ever to find a better one if we abandon it ... I advise long reflection before we move further in to no-fault compensation for medical accidents. Is this really the most pressing marginal case for the deployment of money from the health programme?*”<sup>580</sup>

This intervention led to the Secretary of State, on 5 December 1991, consulting his ministerial colleagues: Baroness Gloria Hooper, Stephen Dorrell and Virginia Bottomley (later Baroness Bottomley).<sup>581</sup> Baroness Hooper considered that the Department “*should hold the line however difficult this may be.*”<sup>582</sup> By contrast, Virginia Bottomley and Stephen Dorrell supported the Secretary of State’s position.<sup>583</sup>

While this debate took place, support for a change in the Government’s position was again voiced by a number of MPs.<sup>584</sup>

## Treasury opposition

Meanwhile, Treasury officials advised the Chancellor and the Chief Secretary to refuse the Secretary of State’s proposal. A 3 December 1991 minute acknowledged that the line taken by the Department of Health on why people with haemophilia but not others were given financial support – that “*they were doubly disadvantaged by an hereditary condition as well as acquiring HIV*” – had “*never been a convincing argument – anyone contracting HIV from infected blood is going to derive little comfort from not also being haemophiliac – and it has*

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580 Memo from Sir Christopher France to Colin Phillips 2 December 1991 DHSC0002931\_005

581 Memo from Colin Phillips to Timothy Sands, Richard Armstrong and Anne Burnett 5 December 1991 DHSC0002537\_063

582 Memo from Baroness Hooper to the Secretary of State 5 December 1991 DHSC0002537\_062. She added: “*I am not aware of a sudden pressure via correspondence or otherwise.*” In evidence to the Inquiry, Baroness Hooper explained that “*I had the deepest of sympathies for those infected with HIV via transfusion / tissue transfer, as well as haemophiliacs. To the extent I could, I endeavoured to make the right decisions based on the advice of those best placed to provide it. Ministers involved often had difficult decisions to make and did not always agree on the best course of action to take in making those decisions. There were many competing interests which needed to be considered and balanced against the inevitable limitations of the DH [Department of Health] budget. Although I indicated that we should continue to ‘hold the line, however difficult this may be’, I would have respected the motivations and decisions of other ministers who took a different view to the one that I had reached.*” Written Statement of Baroness Gloria Hooper para 27.25 WITN7005001

583 Virginia Bottomley’s response noted that she had “*always been cautious in this area*” for the reasons outlined in the Permanent Secretary’s minute. Stephen Dorrell’s response recorded that he adopted his position “*Without enthusiasm*”. Memo from Rob Jex to Colin Phillips 10 December 1991 DHSC0002938\_004, Memo from Helen Bloomfield to Colin Phillips 11 December 1991 DHSC0002537\_242

584 This can be seen, for example, in a 12 December 1991 House of Commons debate, particularly in a contribution by Sir Michael McNair-Wilson MP, and a 25 November 1991 Notice of Motion. Hansard extract on compensation for people infected with HIV through contaminated blood 12 December 1991 DHSC0002437\_065, Notices of Motions on National Health Service Blood/Tissue Transfer (HIV Infection) 25 November 1991 DHSC0002913\_002

*not gone down well in public. But we accept that it is difficult to come up with a better one.*” Similarly, the minute advised that, at the time of the HIV litigation settlement, it was clear that *“there is very little moral difference”* between the case for people with haemophilia who had been infected and others, but it was *“recognised that providing compensation to the second group would take a further step down the slippery slope towards no-fault compensation for medical (and possibly other) claims.”*<sup>585</sup>

Consistently with this advice, on 13 January 1992, the Chief Secretary, David Mellor, responded to the Secretary of State, refusing his request. He explained that he had *“serious reservations about whether it would be possible realistically to ring fence any such compensation”* and commented that, by *“compensating those acquiring HIV from blood transfusion, we will be taking a further long stride towards no-fault compensation in general.”*<sup>586</sup>

The Treasury’s opposition was significant. Even if the Department of Health wished to create a payment scheme without additional funds from the Reserve, it could not do so without approval from the Treasury.<sup>587</sup>

In oral evidence to the Inquiry, David Mellor suggested that there was never any likelihood that payments would not be extended to transfusion patients, and no merit in the distinction between people with haemophilia and transfusion recipients infected with HIV, but that *“there needed to be a bit of grief along the way ... people can’t have easy wins. If you are the Treasury you have to lose in a tough minded way”*.<sup>588</sup>

Notwithstanding the Treasury’s response, Department of Health officials and the Secretary of State continued to consider the issues, including how the money for a payment scheme could be found.<sup>589</sup> On 27 January 1992, the Secretary of State responded to the Chief Secretary,

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585 Memo from Graeme Dickson to Joe Grice and David Mellor 3 December 1991 p2 HMTR0000003\_043

586 The letter also referred to another issue: overpayments to doctors and dentists, which amounted to very significant sums and would require use of the Treasury Reserve. The Chief Secretary suggested that the Secretary of State had thereby left him *“no room to help you or the other health departments by providing additional access to the Reserve for the blood transfusion patients.”* Letter from David Mellor to William Waldegrave 13 January 1992 HMTR0000003\_051. The response followed discussions between the Chief Secretary and his officials in early January 1992. Memo from Graeme Dickson to David Mellor 10 January 1992 HMTR0000003\_050

587 As well as being reflected in the contemporaneous documentation, this point was addressed in evidence to the Inquiry. For example, Lord Waldegrave explained: *“Even though it was now proposed that a Department of Health budget was to be used, the Treasury would still need to approve it. A spending minister cannot initiate a new policy which the Treasury sees as having wider implications and consequences even if he or she chooses to find the money by less spending on another policy already agreed by the Treasury.”* Written Statement of Lord William Waldegrave para 4.134 WITN5288001. Similarly, David Mellor explained in oral evidence: *“Just because you have got the money and you could spend it, doesn’t mean you are able to. If the purpose for which the money was provided is different from the purpose for which it is used, then, yes, the consent of the Treasury would be required.”* David Mellor Transcript 19 May 2022 p182 INQY1000209

588 David Mellor Transcript 19 May 2022 pp190-192 INQY1000209

589 See for example a 17 January 1991 minute from Peter Kendall to the Secretary of State. While noting that it would not be easy, this explained that there was *“no doubt that a sum around £12 million (the present best guess of what will be needed) could be found from the Departmental Votes in 1992-1993 if Secretary of State sees this demand as an overriding priority.”* Letter from Peter Kendall to Colin Phillips 17 January 1992 p1 DHSC0002929\_007

disputing the link the latter had made between an extension of payments to transfusion payments and a separate issue concerning overpayments to doctors and dentists.<sup>590</sup>

Treasury officials subsequently provided the Chief Secretary with three options for his response to the Secretary of State, recommending that he maintain his existing stance. Two other options outlined in the minute, which were not recommended, were to provide the extra £6 million sought by the Department of Health, or to refuse access to the Reserve but allow a payment scheme to be established from the Department's own resources.<sup>591</sup>

While this debate took place, the Department of Health's public position remained that financial support for those infected with HIV would not be extended beyond people with haemophilia.<sup>592</sup>

## February 1992: involvement of the Prime Minister

In early February 1992, a significant step towards the extension of financial support to transfusion patients took place. On 3 February, ahead of a meeting with John Marshall, the Prime Minister, John Major, was provided with a Department of Health briefing.<sup>593</sup> It was clear in its support for the existing ring-fence round people with haemophilia. However, the Prime Minister also received a cover note on the issue from William Chapman, his Private Secretary. Having noted that the Secretary of State had "*still not given up hope of extending help*" but was "*meeting Treasury resistance*", William Chapman commented:

*"Surely the Government will sooner or later have to give way on this one? And the sooner it does so the more credit it can rescue. Treasury argue that it is difficult to ringfence the case of people infected with HIV so that special groups who have suffered at the hands of the NHS will not have a precedent to claim compensation. However, this seems to ignore a couple of points:*

- *the other groups which are thought to be in the wings ... are all suffering from non-fatal diseases. HIV, by contrast, is probably the inevitable first step to AIDS and is almost certainly a death warrant;*
- *in a sense, the pass has already been sold by the granting of aid to haemophiliacs; the Government argues that they are a special case because their lifelong condition has been exacerbated by HIV, unlike*

590 The letter commented that the Secretary of State recognised "*the difficulty in providing resources from the Reserve which your officials have explained to mine*" and that he would "*investigate what scope there may be for longer term action on the blood transfusion patients.*" He also added in manuscript: "*Though I remain firmly of the opinion that the provision of £6m from the reserve to match £6m which I believe I can find (just) from existing provision – remains politically and morally the correct course.*" Letter from William Waldegrave to David Mellor 27 January 1992 DHSC0002925\_009

591 Officials also recommended that the Chief Secretary request the return of the £6 million the Secretary of State had said he could contribute to the payment scheme to defray the overpayments to doctors and dentists. Memo from Joe Grice to David Mellor 31 January 1992 HMTR0000003\_055

592 As reflected for example in a briefing for the Secretary of State for a meeting with Sir Michael McNair-Wilson MP and Gavin Strang MP. Briefing for HIV Infection resulting from NHS Blood/Tissue Transfer meeting p2 DHSC0002923\_001

593 Briefing for Number 10 on HIV Infected Blood/Tissue Recipients CABO0000044\_012



*non-haemophiliacs who have been healthy up until the time of their need for a blood transfusion. This cannot be true because some of the latter must include, for example, people suffering from leukaemia.”*

William Chapman added that the “*Government’s position seems increasingly untenable.*”<sup>594</sup>

In addition, the Treasury’s position had by this time begun to change. A 5 February 1992 minute recorded the Chief Secretary’s decision that he “*would be willing to agree to Mr Waldegrave proceeding with compensation if it was agreed that no further groups would be given similar treatment; and if Mr Waldegrave found all the necessary funds.*”<sup>595</sup>

On 7 February 1992, following the Prime Minister’s meeting with John Marshall and other MPs, the Secretary of State wrote to him to make the case for extending financial support to transfusion patients infected with HIV. In doing so, he acknowledged that the Government had to “*recognise the risk of weakening our general opposition to no fault compensation*” and suggested that it should make plain that it was responding to “*very special circumstances*”. He also addressed a proposed division of funding between the Department and Treasury.<sup>596</sup> Lord Waldegrave told the Inquiry that he involved the Prime Minister as “*Without his support, I could not have introduced the scheme extension.*”<sup>597</sup>

On the same day, the Chief Secretary wrote to the Secretary of State to communicate the Treasury’s change of position. While reiterating his concern about ring-fencing and moving towards no-fault compensation, he explained that he was “*willing to withdraw my objection provided you are able to give a firm assurance that you and your department will be prepared to draw the line at this group and to face up to requests from other groups.*” He further asked that the Department of Health find the necessary funding without any contribution from the Treasury Reserve.<sup>598</sup>

Further correspondence between the Prime Minister’s office, the Department of Health and the Treasury continued on the details and timing of the Government’s announcement that it would be extending financial payments.<sup>599</sup> On 12 February 1992 the Secretary of State responded to the Chief Secretary, referring to the difficulty in drawing “*watertight borderlines*” in this area and commenting that “*a borderline covering all those infected with HIV by NHS treatment in the UK involving whole blood/blood products and organ transplants would be more defensible.*” As for funding, the Secretary of State noted that he would have to review

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594 Memo from William Chapman to the Prime Minister 3 February 1992 CABO0000044\_011. The discussion at the Prime Minister’s meeting with John Marshall and four other MPs was recorded in a 5 February 1992 note from William Chapman to the Department of Health. It noted that the Prime Minister had highlighted the risk of a precedent being set which would lead to no-fault compensation, as well the importance of a clear ring-fence, and that he had agreed to consider the matter further. Letter from William Chapman to Chris Padwick 5 February 1992 CABO0000044\_023

595 Letter from Nicholas Holgate to Joe Grice 5 February 1992 HMTR0005118\_005

596 Letter from William Waldegrave to the Prime Minister 7 February 1992 HMTR0000003\_063

597 Written Statement of Lord William Waldegrave para 4.145 WITN5288001

598 Letter from David Mellor to William Waldegrave 7 February 1992 CABO0000044\_024

599 This included two minutes from the Prime Minister’s Office to the Department of Health. Letter from William Chapman to Paul Ahearn 10 February 1992 HMTR0000003\_067, Letter from William Chapman to Chris Padwick 11 February 1992 HMTR0000003\_066

his overall programme to seek to find the necessary funding within the Department.<sup>600</sup> As foreshadowed in this correspondence, the payment scheme was ultimately funded without a contribution from the Treasury Reserve.

## Announcement of the change

The change in the Government's position became public on 17 February 1992, when it was announced that financial support for people with haemophilia infected with HIV would be extended to those infected as a result of blood transfusion or tissue transfer in the UK. The scheme would include spouses, partners and children to whom infection may have been passed on. The announcement explained that the circumstances of each infected person would need to be considered individually to establish that treatment in the UK was the source of their infection and that a small expert panel was being set up to consider cases where necessary. It was noted that "*Further detailed work needs to be done on the machinery for handling individual claims for the payments; but payments will be made as soon as possible.*" The estimated cost was £12 million but the Department of Health could not be certain about this as the number of valid claims was not known.<sup>601</sup>

Three days later, on 20 February 1992, officials sought the Secretary of State's agreement to the outline of a payment scheme. The submission explained that many aspects of the proposed scheme were modelled on the equivalent for people with haemophilia infected with HIV but that there would be "*particular problems over the validation of claims from blood and tissue recipients and we shall need an expert panel to sift the available evidence and make decisions which will be difficult in some cases.*" This was said to mean that "*the process of making payments is likely to be more protracted than for most haemophiliacs.*"<sup>602</sup>

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600 Letter from William Waldegrave to David Mellor 12 February 1992 DHSC0002582\_003. Emphasis in the original. The Chief Secretary responded on 14 February 1992, accepting the Secretary of State's judgement that he would be able to defend a borderline which included all of those infected with HIV as a result of blood transfusion; noting that the funding would come within the Department of Health's existing resources (with the other health departments funding their share of the settlement). Letter from David Mellor to William Waldegrave 14 February 1992 CABO0000044\_030

601 The announcement reiterated that the Government remained against introducing a no-fault compensation scheme; instead, the Secretary of State had concluded that it would be right to recognise that the group of patients infected by blood transfusion or tissue transfer, "*which shares the tragedy of those with haemophilia in becoming infected with HIV through medical treatment within the UK, is also a very special case.*" Department of Health Press Release *Government Announces Help for HIV Infected Blood Transfusion Recipients* 17 February 1992 DHSC0002578\_001, Hansard parliamentary question on HIV Blood Transfusions 17 February 1992 DHSC0003625\_040. Notes in the press release containing the announcement recorded that, at the end of December 1991, there were 74 reports of HIV infection in people who received blood transfusions or tissue transfers in the UK, 17 reports where the place of transfusion was unknown and that there may be some cases which had not yet been reported.

602 One difference, as recorded in the submission, was that the HIV litigation settlement included a payment of £2,000 for uninfected family members taking legal action on the grounds that they were at risk from the infected haemophilia patient. It was said that this "*claim was not well founded but would have been difficult to end the litigation without making some payment*", though relatives outside the litigation were not paid the £2,000. Officials proposed not to make such payments in blood transfusion/tissue cases; to "*entertain claims from uninfected relatives could prompt claims from the non-litigant relatives of haemophiliacs.*" Fax from Roger Scofield to Dr Harold Gunson 20 February 1992 p2, p5 NHBT0015117\_001, Annex on Scheme of Financial Help for those Infected with HIV through Blood or Tissue Transfer DHSC0002642\_004

As for the scope of the scheme, it was proposed that it would cover those people who had been infected with HIV in the course of receiving medical treatment; as well as recipients of infected blood transfusion and tissue transfer, this would include people without bleeding disorders infected with HIV through treatment with fractionated blood products. The submission explained that applying a cut-off date after the introduction of HIV screening in October 1985 would be difficult because infection could still be transmitted from a donor who was in the “window period” at the time of testing. Instead, *“claims of infection from blood or tissue after 1985 would have to be examined particularly closely in view of the safeguards then in place.”*<sup>603</sup>

As for validating claims, where the status of the donation could not be firmly established, it was proposed that the case be considered on the balance of probabilities: *“this would include the timing of the transfusion/tissue transplant; clinical history of the case and limited consideration of lifestyle, eg is there a record of treatment for drug abuse; questions could be asked about associations with high risk countries.”*<sup>604</sup>

The submission also discussed access to *“special needs payments”*, as had been created for people with haemophilia through the Macfarlane Trust, and which was said to be necessary in order *“to make a clean break with the problem of the blood transfusion/tissue cases”*. This could be done either by extending the remit of the Macfarlane Trust<sup>605</sup> or by setting up a new charitable trust. Either way, it was *“likely that some money, say £½ M, would have to be found to endow a new trust or to avoid the appearance of diluting the haemophiliac fund”*.<sup>606</sup>

As well as agreeing to the outline of the scheme, the Secretary of State was asked to confirm that he was content for officials to begin discussions on it with the various interested parties.<sup>607</sup>

The Secretary of State confirmed his agreement to the approach proposed by officials on 2 March 1992.<sup>608</sup>

## Commentary

A number of factors contributed to the Government’s eventual change of position on payments to individuals infected with HIV by blood or tissue transfer. In written evidence to the Inquiry, Lord Waldegrave commented that media coverage helped the Government to see that its policy of distinguishing transfusion patients from people with haemophilia infected with HIV was failing to convince.<sup>609</sup> Similarly, he stated that the *“combined increased pressure in*

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603 Fax from Roger Scofield to Dr Gunson 20 February 1992 p3 NHBT0015117\_001

604 Fax from Roger Scofield to Dr Gunson 20 February 1992 p4 NHBT0015117\_001

605 It was noted that the trustees might not agree to this.

606 Fax from Roger Scofield to Dr Gunson 20 February 1992 p5 NHBT0015117\_001

607 In addition, the Secretary of State was asked to agree that the Department of Health would pay the reasonable legal costs of individuals who had brought blood transfusion/tissue transfer claims. Fax from Roger Scofield to Dr Gunson 20 February 1992 pp6-7 NHBT0015117\_001

608 Memo from Colin Phillips to Roger Scofield 2 March 1992 DHSC0002653\_004. One comment from the Secretary of State was recorded: *“careful legal advice”* would be needed on validation decisions taken on the balance of probabilities, as these would be subject to judicial review.

609 Written Statement of Lord William Waldegrave para 4.112 WITN5288001

*Parliament (questions, motions and debates), from the media campaign and from allied correspondence, led me to judge that the government's position was not sustainable.”*<sup>610</sup>

Two features of this decision-making process stand out. First, the decision-making process took too long. Second, despite some politicians being responsive to the claims that people who had been infected with HIV by their treatment should be given financial support, civil servants remained determined in their opposition to this.

As to the first, when in November 1987 it had been decided to provide ex gratia support for people with haemophilia who had been infected with HIV, a Cabinet Sub-Committee concluded that transfusion recipients had a very strong claim for inclusion in any payment scheme – although any scheme should be ring-fenced.<sup>611</sup> It might have been thought that an obvious ring-fence could have been infection by treatment on the NHS with the AIDS-causing virus. Ultimately, this was the ring-fence for ten years before Hepatitis C infections were also recognised as demanding support.

From at least December 1990 and certainly by January 1991, the weakness of the distinction the Government sought to make between people with haemophilia and people infected by blood or tissue transfer had been made clear by campaigners.

Lord Waldegrave's evidence to the Inquiry was that it took until February 1992 for the Government to change its position because *“it took that length of time to overcome the arguments of precedent, which were real.”*<sup>612</sup>

Similarly, in his written evidence, Sir John Major commented that the *“Government is sometimes like a great tanker and takes time to turn around; an example of this is with regard to payments to non-haemophilia patients who contracted HIV through a blood transfusion.”* He added that the Government *“does have to go through arguments on precedent, need and affordability before alighting on the right policy. Treasury caution on expenditure cannot be lightly set aside because their responsibility to control overall expenditure is crucial to both the economy and the taxpayer.”*<sup>613</sup>

In oral evidence, Sir John Major added that *“the concern about no-fault compensation and the direction in which that could go was a genuine worry with the Treasury, at a time when other budgets were being chopped because of the inflationary spiral that we were seeing in the early '90s, and more expenditure would mean more reductions elsewhere.”* He

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610 Written Statement of Lord William Waldegrave para 4.119 WITN5288001

611 Minutes of Home and Social Affairs Committee Sub-Committee on AIDS meeting 10 November 1987 p9 CABO0100016\_011

612 Lord William Waldegrave Transcript 6 July 2022 p37 INQY1000221. Similarly, while Lord Waldegrave faced resistance from the Treasury between December 1991 and February 1992 following the change in his view, he made no criticism of the Treasury for this. He commented: *“But I would add that the Treasury were doing their job here. Unpopular though it may be, they have to analyse critically new significant spending plans, particularly those which may set a precedent leading to even greater future spending. I do not criticise the Treasury for the points they were making. Indeed having later been Chief Secretary to the Treasury myself, I can well understand why they were being made.”* Written Statement of Lord William Waldegrave para 4.129 WITN5288001

613 Written Statement of Sir John Major paras 3.52-3.53 WITN5284001

explained that he would not “*argue with the argument that it could have been done sooner. I can only say in retrospect you could often see things a little more clearly than you can when you have a dozen other things in front of you at the same time and perhaps that was true of everyone involved.*”<sup>614</sup>

I accept the general point that policies which require significant expenditure may need to be developed incrementally rather than all at once. There is also little doubt that fears about a precedent being set were real, though as already pointed out once a decision had been taken to establish the Macfarlane Trust the obvious ring-fence was around the nature of the disease transmitted by NHS treatment rather than the condition which caused people to seek treatment in the first place.

However, while these considerations were no doubt real, they do not justify the lengthy period it took for the Government to change its position. Sir John Major was right to accept that he would not argue against a conclusion that this could have been done sooner.<sup>615</sup> David Mellor’s suggestion to the Inquiry in oral evidence that there never was any likelihood that payments would not be extended to transfusion patients, but (in effect) that they had to fight for it<sup>616</sup> underscores this point as to delay, for the policy he described amounted to a deliberate refusal to pay earlier than could have been the case so that others, with different cases to propound, might be more easily fended off. In essence – “we are going to pay; you should be paid; but not just now – later.”

The significance of this for present purposes is that context was crucial: patients had been infected several years earlier with a life-altering virus, with consequences as serious as they were well-known. Treatment possibilities were extremely limited. Patients and their families did not have time on their side. The Government should have recognised that its position was logically unsustainable (as it might be thought David Mellor indicated he realised) and should have changed course significantly earlier than it did. If any group was to be kept waiting, it should not have been this one.

As to the second feature, briefing notes from the Department of Health demonstrate repeated concern about the risk that payment to the (relatively small) group of those who had suffered HIV as a result of transfusion might set a precedent for no-fault compensation; John Canavan spoke of a change of mind as being a “*cave-in*”.<sup>617</sup> Strachan Heppell expressed misgivings about Lord Waldegrave’s change of policy.<sup>618</sup> The Permanent Secretary argued that “*we are unlikely even to find a better [ring-fence] if we abandon [the one around haemophilia]*”<sup>619</sup> Treasury officials took a similar course – though describing the then current justification for limiting financial support for people who had suffered HIV infection from treatment under the

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614 Sir John Major Transcript 27 June 2022 p136 INQY1000219

615 Sir John Major Transcript 27 June 2022 p136 INQY1000219

616 David Mellor Transcript 19 May 2022 pp190-192 INQY1000209

617 Memo from John Canavan to Paul Ahearn 31 May 1991 DHSC0002913\_008

618 Memo from Strachan Heppell to Colin Phillips 28 November 1991 DHSC0002894\_011, Memo from Strachan Heppell to Colin Phillips 29 November 1991 DHSC0002537\_262

619 Memo from Sir Christopher France to Colin Phillips 2 December 1991 DHSC0002931\_005

NHS to people with haemophilia as never having been convincing, they urged that there should be no extension.<sup>620</sup> There is a strong sense that departmental officials were keen throughout to advise their ministers of the risks, rather than the justice, of a change in policy.

Whilst the Government deliberated, those infected with AIDS through transfusion were suffering and dying. Two cases will suffice to reinforce why it was so important for a decision to be taken sooner than it was. The first is described in the supplementary report of the Inquiry's intermediaries:

*“One family described their mother’s deep distress that no financial support was available to her although she had been infected with HIV through a transfusion. At that time, financial support was being offered only to people with haemophilia. She was understandably embittered about this as she desperately wished to give her children some financial foundation for their future. She had no savings and was unable to work.”*

She died without receiving any such support.<sup>621</sup> The second case involves a young woman who received a two-unit blood transfusion following the birth of her first child in 1982 and was infected with HIV as a result. Her second child was infected in utero.<sup>622</sup> She died in 1986 from AIDS, aged just 21 years old, and her child died at the age of three. Her husband was also infected with HIV. He told *The Observer* in May 1991 that he only had a limited amount of time left. *“The Department of Health should give financial help to those who need it so they don’t have to go to court and waste the rest of their lives trying to get a few thousand pounds. People shouldn’t have to go cap in hand trying to prove they are entitled to compensation. Everybody knows we are morally entitled to it.”*<sup>623</sup> By August 1994 he too was dead. Only the first child was left alive, having lost his mother, sister and father as the consequence of one transfusion.

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620 Memo from Graeme Dickson to Joe Grice and David Mellor 3 December 1991 HMTR0000003\_043

621 Intermediaries' Report: Supplementary p10 2 June 2023 WITN4000002

622 Newcastle Upon Tyne Coroners Court Inquest Report 1987 p9 CRNC0000018

623 *The Observer Pressure for action grows* 26 May 1991 HSOC0001454

## 6.5 Eileen Trust

The Eileen Trust was established to provide funds to people who were infected with HIV as a result of receiving infected blood or tissue. This chapter compares and contrasts the Eileen Trust with the much larger Macfarlane Trust and considers the relations between trustees and beneficiaries and the funding of the Trust by the Department of Health.

### Key Dates

**29 March 1993** the Trust formally begins with initial capital funding of £500,000.

**August 1993** the Trust pays regpay to registered beneficiaries.

**January 1994** the Trust increases the amount of regpay to registered beneficiaries.

**March 1994** a health-related supplement is included in regpay.

**1998** widows and widowers with children of qualifying persons start to receive regpay.

**1999** first handbook for registrants produced.

**23 May 2007** Peter Stevens provides evidence to the Archer Inquiry that successive governments have failed to provide adequate funding to the Trust.

**March 2008** Trustees note “*intense disappointment and dissatisfaction*” with the “*substantial reduction in their means of meeting the objects of the Trust*”.

**May 2009** the Government announces that it will increase funding in response to Lord Archer’s report.

**1 November 2017** the Trust ceases functioning and decides to distribute the remaining funds between registered beneficiaries.

### People

**Peter Stevens** chair, Eileen Trust (2000 - 2018)

**Reverend Alan Tanner** chair, Eileen Trust (1993 - 2000)

### Abbreviations

**Regpay** regular payments made by the Trust to beneficiaries

People who became infected with HIV as a result of receiving infected blood or tissue but who did not have haemophilia were beyond the scope of the Macfarlane Trust. Although they suffered from the same infections, with similar consequential effects, as did people with haemophilia, the Government did not recognise them as meriting ex gratia support. It changed its mind in response to media pressure, and pressure from politicians.<sup>624</sup> Its response was to establish a charity with initial capital funding of £500,000.

On 10 April 1992 the Secretary of State for Scotland established a scheme of payments for those “*infected with HIV through blood or tissue transfer*”. The scheme for England, Wales and Northern Ireland was established on 24 April 1992, a fortnight later. The schemes provided for the payment of fixed sums to people infected and people indirectly infected<sup>625</sup> in different categories, depending on whether they were adult or younger, were married, and whether they had dependent children.<sup>626</sup>

The Eileen Trust formally began on 29 March 1993. The object of the Trust, as established by a deed of that date, was “*to relieve those qualifying persons who are in need of assistance or the needy dependants of qualifying persons and the needy dependants of qualifying persons who have died.*”<sup>627</sup> “*Qualifying person*” was defined as “*a person who has received or is entitled to receive a payment ... under the scheme of payments for those infected with HIV through NHS blood or tissue transfer ... other than an infected intimate as defined in that [either] scheme.*”<sup>628</sup>

It was envisaged initially that there would be five trustees. Three trustees were appointed by the deed of March 1993: Reverend Alan Tanner, Alan Palmer and Dr Elizabeth Mayne. At the first meeting of the trustees, Reverend Tanner was confirmed as chair. The turnover of trustees was low.

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624 See the chapter on *Government Response to HIV Infections through Blood or Tissue Transfer*. The media pressure included a campaign in *The Observer* and an 11 May 1991 report in *The Times* that a campaign for transfusion patients infected with HIV was being launched following settlement of the HIV litigation. The *Observer This little baby was killed by the NHS* 26 May 1991 ARCH0002829\_005, The *Observer Illogical, Indefensible, Unjust* 26 May 1991 HSOC0001454, The *Times HIV transfusion victims launch payment claim* 11 May 1991 DHSC0006473\_028. Political pressure included parliamentarians such as Robin Cook MP who wrote on 31 January 1991 to the Secretary of State expressing the view that the distinction between people with haemophilia and those without haemophilia was untenable. Letter from Robin Cook to William Waldegrave 31 January 1991 p1 DHSC0002850\_004. In his written statement William Waldegrave, then Secretary of State for Health stated that “*combined increased pressure in Parliament (questions, motions and debates), from the media campaign and from allied correspondence, led me to judge that the government’s position was not sustainable.*” Written Statement of Lord Waldegrave para 4.119 WITN5288001

625 Those indirectly infected were often referred to as “*infected intimates*” in contemporaneous documents. Many to whom this term could apply understandably found the expression distasteful.

626 Scottish Home Office and Health Department Scheme of Payments for Those Infected with HIV through Blood or Tissue Transfer 10 April 1992 SCGV0000239\_016, Eileen Trust Scheme of Payments for Those Infected with HIV through Blood or Tissue Transfer 24 April 1992 EILN0000016\_001

627 Entitlement beyond those people infected with HIV was thus limited to those who were “*dependent*”, a more limiting description than that of the classes of person entitled to benefit under the terms of the Macfarlane Trust – see the *Macfarlane Trust* chapter.

628 Declaration of Trust Constituting the Eileen Trust 29 March 1993 clauses 1(e), 3 pp3-4 EILN0000016\_017



The administration was in the hands of a secretary, a role taken by the chief executive of the Macfarlane Trust. That position changed after Martin Harvey was succeeded by Susan Daniels, who had worked for beneficiaries of the Eileen Trust<sup>629</sup> as an independent financial adviser and as a case worker. She had been recruited to that role by Peter Stevens, who succeeded Reverend Tanner as chair. The Eileen Trust had a social worker and benefits advisor. These staff were (broadly) shared with the Macfarlane Trust for ease of administration, and to take advantage of established experience.

The numbers were small by comparison with the Macfarlane Trust. The total number of registrants remained in the region of 20 to 30 at any one time, though it varied from year to year. New registrants emerged from time to time; but the number was rather lower than the number the Government had supposed would be likely to make a claim on the Trust as having been infected with HIV by blood transfusion or tissue transfer.<sup>630</sup> This may in part have reflected the fact that some had already died before the scheme was even established.

Although the Eileen Trust was administered by the same staff who administered the Macfarlane Trust, its board made the decisions which it thought best for the Eileen Trust.<sup>631</sup> It paid regpay<sup>632</sup> (from August 1993 onward) with increases in January 1994 and a health-related supplement from March 1994. Widows and widowers with children received regpay by at least 1998.<sup>633</sup> Indeed, the board preferred beneficiaries to have regular income from the Trust to avoid the necessity to apply for single grants, and to afford them greater personal control over their expenditure.<sup>634</sup>

Following a Macfarlane Trust “Away Day” in 2006 after which it was reported to the Eileen Trust board by Peter Stevens that the advice had been that “*financial need is an absolute prerequisite for any disbursement by a charity*”,<sup>635</sup> the Eileen Trust adopted receipt of income support and the earning of a minimum wage as reasonable indicators of financial need. Following increased funding provided by the Government in response to Lord Archer’s report,<sup>636</sup> the board decided to adopt a minimum level of income which registrants should have, determined by taking into account whether they were single, lived with a partner and had children.<sup>637</sup>

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629 As well as the Macfarlane Trust.

630 The Eileen Trust Annual Report and Accounts for the period ending 31 March 1994 p4 EILN0000016\_060. Eligibility was determined by the Department of Health and by the Scottish Home and Health Department in Scotland. There was no time bar nor prescribed time period before or within which the causative treatment had to have occurred.

631 Sue Phipps Transcript 12 March 2021 pp14-15 INQY1000109

632 Regular payments made by the Trust to beneficiaries.

633 Minutes of Eileen Trust meeting 16 October 1998 p4 EILN0000006\_079

634 The Eileen Trust Annual Report and Accounts for the period ending 31 March 1994 p5 EILN0000016\_060

635 Email from Peter Stevens to Dr Mark Winter, Pat Spellman, Sue Phipps and Susan Daniels 13 November 2006 p1 MACF0000051\_057

636 Government Response to Lord Archer’s Inquiry Report 20 May 2009 p8 HSOC0011282\_002

637 Minutes of Eileen Trust meeting 24 February 2010 p2 EILN0000012\_018

Single grants were applied for and provided on a case-by-case basis, on the basis of either financial or health need.<sup>638</sup> No record of income or expenditure was needed in order to make an application. A handbook for registrants was not produced until 1999.<sup>639</sup> Regular contact with office staff and case workers allowed registrants of the Eileen Trust to know what they could apply for and there were newsletters which Sue Phipps told the Inquiry she had been involved in making less dense and more accessible.<sup>640</sup>

## Commentary

The Eileen Trust did not suffer to the same extent from the difficulties which beset registrants of the Macfarlane Trust. There was a similar lack of information given to beneficiaries and a similar degree of subjectivity in the assessment of individual grant applications, but the relations between the trustees and the beneficiaries did not give rise to similar problems.

A principal problem was identifying those who might benefit, one which was far less of a problem in the case of the Macfarlane Trust. The Eileen Trust did not have the staff or resources to conduct a publicity campaign to advertise its existence. Moreover, to do so might be to expose applicants for membership to the risk that it might become known that they were infected with HIV. Such had been the stigma attaching to those infected with HIV or living with AIDS that this would have created reluctance to apply. Perhaps indicative of this, as at 31 March 1994, 57 people were known to have qualified under the schemes for lump sum payments at the outset, but of those only 24 (less than half) had actually made contact to register with the Trust.<sup>641</sup> The trustees arranged that the Department of Health should contact potential beneficiaries who had not yet registered. The Trust wrote to “*medical and social work staff at hospitals and to contacts in voluntary organisations connected with HIV giving information about the Trust and inviting referrals*”. The staff took action where they

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638 There was no set procedure for making applications for grants, the Macfarlane Trust office guidelines were used by the case worker when considering applications for grants, but these were confidential and were not shared with beneficiaries. Office guidelines for grants January 2005 EILN0000003\_179. In September 2004 Susan Daniels identified a need for clearer guidelines to be published so that registrants would know what was available to them and their dependants. “*Since the last report it has become evident that clearer guidelines need to be published which are simple and easy to understand by the registrants. They need to know exactly what is available to them and whether it is available to registrants only or their dependants as well.*” Financial Advisors Report 27 September 2004 EILN0000011\_197. There were no policies, written or otherwise, that set out how to determine applications made to the Eileen Trust and they were determined on a case by case basis: Sue Phipps agreed in her evidence to the Inquiry that assessing applications in this way gave rise to a risk that they were assessed in an inconsistent and unfair way. Sue Phipps Transcript 12 March 2021 pp50-51 INQY1000109. Sue Phipps was a trustee 1993-2017.

639 Minutes of Eileen Trust meeting 29 January 1999 p2 EILN0000006\_066, Eileen Trust Handbook EILN0000007\_029

640 Sue Phipps Transcript 12 March 2021 pp47-49 INQY1000109. The board decided in 2002 to produce another version of the handbook and publication of the handbook continued to be budgeted for until 2011, but no revised handbook has become apparent to the Inquiry.

641 The Eileen Trust Annual Report and Accounts for the period ending 31 March 1994 p4 EILN0000016\_060

could identify someone who might be a registrant who had not yet applied. Yet the numbers of those who claimed remained low.<sup>642</sup>

Unlike the Macfarlane Trust, the board did not consider that support from the Eileen Trust should necessarily be secondary to that from state benefits.<sup>643</sup> A further contrast is that in 2017, when the Eileen Trust was to cease functioning as the four national schemes took over, its trustees decided that until the handover on 1 November 2017 grants would continue to be made as usual, but that any funds remaining after that would be distributed between the registrants.<sup>644</sup>

A second problem, arising from the way in which the Trust was set up initially, resembled that which so beset the Macfarlane Trust: the problem of inadequate funding.<sup>645</sup> But in the case of the Eileen Trust it was subtly different. The numbers of beneficiaries of the Macfarlane Trust who had been directly infected reduced over time; by contrast, the numbers of beneficiaries of the Eileen Trust increased as more individuals became aware of its existence.

There was very little problem with knowledge of the Macfarlane Trust scheme for those entitled, because of the communities of people with haemophilia which had naturally grown up around their treatment centres, the membership of many in the Haemophilia Society, and the familiarity of treating clinicians with the existence of the Trust gained from the numbers of their patients who would be eligible. By contrast, people infected with HIV by transfusion had no such community of fellow sufferers, nor clinicians to whom the existence of the Trust was familiar. Their comparative isolation was no doubt exacerbated by knowledge of the

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642 The Eileen Trust Annual Report and Accounts for the period ending 31 March 1995 p4 DHSC0002779\_002. In addition to recording the actions taken by the Trust, the annual report noted that as at 31 March 1995 the number of people who had received a payment from the Government had gone up from 57 to 62 and the number registered with the Trust had increased from 24 to 34.

643 In his evidence to the Archer Inquiry, Peter Stevens referred to the Eileen Trust as “*the first line of support*”. Written Statement of Peter Stevens to the Archer Inquiry 23 May 2007 p4 ARCH0002992. Though he gave evidence to the Inquiry that: “*I’m not sure that that first paragraph is entirely accurate ... We would always ask people went somewhere else and looked at us as the fall-back.*” Peter Stevens Transcript 24 February 2021 p69 INQY1000099. Nonetheless the statement to the Archer Inquiry is indicative of a less stringent approach (compared to the Macfarlane Trust) to ensuring that the Trust funds were always the last resort. Thus though Susan Daniels said that the approach of the Eileen Trust was broadly similar to that of the Macfarlane Trust she also said she had a discretion about whether to require quotes for an item of proposed expenditure. Susan Daniels Transcript 10 March 2021 p71 INQY1000107. The smaller number of beneficiaries clearly allowed a more tailored approach. For instance, in February 2003, the board minutes say: “*The Chairman suggested that it would be possible to revisit each Eileen Trust case and see of [sic] there were more appropriate ways of providing financial assistance to them. The formula based on receipt of state benefits and family status was not necessarily the most effective way of helping people.*” Minutes of Eileen Trust meeting 26 February 2003 p2 EILN0000013\_346

644 Minutes of Board of Trustees meeting 7 September 2017 p1 EILN0000002\_026

645 The Eileen Trust, like the Macfarlane Trust, was at first funded by ad hoc payments – an initial settlement of £500,000 in March 1993 with a further payment of £500,000 in March 2002. The Eileen Trust Annual Report and Accounts for the period ending 31 March 1994 p4 EILN0000016\_060, The Eileen Trust Annual Report and Accounts for the year ending 31 March 2002 pp3-4 EILN0000016\_052. Funding became annual from the year ending March 2007 but the annual report and accounts recorded: “*The Trustees have expressed their intense disappointment and dissatisfaction with the block grant funding level for this year, of £177,000, and, even more, with that indicated for next year, of £178,000 (to include administrative expenses) and will continue to attempt to increase funding levels.*” The Eileen Trust Annual Report and Audited Accounts for the year ended 31 March 2007 p5 EILN0000017\_007

stigma which HIV sufferers attracted, and this may have played a part in an individual being reluctant to come forward to seek a form of recognition as someone infected with that virus.

Though numerically the increases were small in comparative terms,<sup>646</sup> proportionally to the total they were significant. They did however hold in common with beneficiaries of the Macfarlane Trust the increasing needs caused by the infection as they grew older. Thus the disbursements made by the Eileen Trust increased.<sup>647</sup> Yet as Peter Stevens recorded in his evidence to the Archer Inquiry: “*the DoH have shown no understanding of, or willingness to increase ET’s funding for, increases in the number of ET [Eileen Trust] registrants.*”<sup>648</sup> He finished his written evidence by saying:

*“Successive Governments have chosen not to provide levels of true compensation that would match their responsibility; they have instead opted to provide ongoing support through ET whose Board of Trustees are charged with the duty to relieve the needs of its beneficiaries. They cannot perform that duty unless adequate funding is provided.*

*The Government must recognise both the fundamental change brought about by the long-term survival of victims and their families, and the fact that the number of ET registrants is growing and is likely to continue to grow. A commitment to substantially increased funding for the Trust and to substantially enhanced capital payments for its registrants is not just essential but also morally irrefutable.”*<sup>649</sup>

The context was a failing of government not even to provide a cost of living increase in the amounts given to the Eileen Trust, let alone provide the same per capita amount for each new registrant as had been given to those who were already registrants, so that each had the same average amount devoted to their support should they need it.<sup>650</sup>

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646 Peter Stevens’ evidence to the Archer Inquiry was that seven new beneficiaries had been registered in the six years prior to his giving evidence, which broadly correlates with the accounts. Written Statement of Peter Stevens to the Archer Inquiry 23 May 2007 p2 ARCH0002992. In the year ending 31 March 2003 there had been three new beneficiaries, one the following year, two new beneficiaries in the year ending 31 March 2005, and a further two the following year with a further new beneficiary the following year: The Eileen Trust Annual Report and Accounts for the year ending 31 March 2002 p2 EILN0000016\_052, The Eileen Trust Annual Report and Accounts for the year ending 31 March 2003 p3 EILN0000016\_051, The Eileen Trust Annual Report and Accounts for the year ending 31 March 2005 p3 EILN0000016\_043, The Eileen Trust Annual Report and Accounts for the year ending 31 March 2006 p3 EILN0000016\_042, The Eileen Trust Annual Report and Audited Accounts for the year ended 31 March 2007 p3 EILN0000017\_007. As late as 2016 the Eileen Trust had two new registrants. The Eileen Trust Annual Report and Audited Accounts for the year ended 31 March 2016 p4 EILN0000016\_030

647 By way of example, in the annual report and accounts for the year ending 31 March 2001 a total of £88,657 was paid out to beneficiaries, by 31 March 2003 the total payments made to beneficiaries was £131,816 and by 31 March 2006 total disbursement funding for the year was £171,138. The Eileen Trust Annual Report and Accounts for the year ending 31 March 2001 p4 EILN0000016\_053, The Eileen Trust Annual Report and Accounts for the year ending 31 March 2003 p4 EILN0000016\_051, The Eileen Trust Annual Report and Accounts for the year ending 31 March 2006 p3 EILN0000016\_042

648 Written Statement of Peter Stevens to the Archer Inquiry 23 May 2007 p3 ARCH0002992

649 Written Statement of Peter Stevens to the Archer Inquiry 23 May 2007 p5 ARCH0002992

650 The Trustees noted in the annual report and accounts for the year ending 31 March 2008 “*their intense disappointment and dissatisfaction*” with the “*substantial reduction in their means of meeting the objects of the Trust*” and stated that it was inevitable that the Eileen Trust would run at a loss in

The approach taken by successive governments was of the same kind as that taken when first funding the Macfarlane Trust: it was one which did not reflect in any meaningful way on the individual needs of any of those beneficiaries it was meant to support. It was instead an arbitrary sum, not linked directly to any true assessment of need.<sup>651</sup>

One of the principal reasons for the greater satisfaction which, broadly, registrants of the Eileen Trust felt when compared with beneficiaries of the Macfarlane Trust was that it dealt with a smaller number of people. An alternative way of expressing this is that the ratio of staff, trustees and caseworkers per head was higher, facilitating a more personal approach for each registrant and a more relaxed approach for each trustee.<sup>652</sup>

The registrants had also not been brought together in small local groups or a national organisation before becoming involved with the Eileen Trust (as Macfarlane Trust beneficiaries had by their common experiences of haemophilia). Nor was there an established society, such as the Haemophilia Society, to which many had previously belonged.

The fact that the operation of the Eileen Trust gave rise to fewer difficulties than the other Alliance House Organisations should not, however, obscure the fact that the ex gratia payments which it was able to make still fell far short of providing meaningful compensation to those infected with HIV through transfusion.

Richard Titheridge whose late wife, Patricia, was infected says *“The Eileen Trust was essentially a charity ... and I’d rather not have charity, it doesn’t sit well with me. If they had originally paid proper compensation ... it would have saved money and dealt with the problem properly.”*<sup>653</sup>

Another man, infected after his mother was given a blood transfusion during her pregnancy with him, says: *“I was very disappointed with the level of financial support I received from the Eileen Trust and I would liken it to ‘having pennies thrown at me’. I remember giving up trying to obtain even £5 towards my travel to hospital due to the fact that I was made to feel as if I was a criminal who was begging for money ... Proper compensation is both*

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some years and have to run down the capital reserves. The Eileen Trust Annual Report and Audited Accounts for the year ended 31 March 2008 p5 EILN0000016\_038

651 A good example of this is the Department of Health’s response to the joint business case submitted to them for the Eileen and Macfarlane Trusts in November 2005. The Macfarlane and Eileen Trusts Funding long-term survival November 2005 MACF0000177\_017. As set out in the chapter on the *Macfarlane Trust*, the response to this was to provide what was affordable, rather than what was required to meet the needs of the beneficiaries. As for the allocation of what was offered between the Trusts (said to be an increase of £400,000 although this was disputed by Peter Stevens as being an increase at all as it incorporated the administrative costs of the Trust) 10% was allocated to the Eileen Trust by the Department of Health based solely on the *“current ratio of their size”*. Letter from Caroline Flint to Peter Stevens 28 July 2006 HSOC0005411, Peter Stevens Transcript 23 February 2021 p134 INQY1000098

652 This was acknowledged by Peter Stevens in his evidence to the Archer Inquiry: *“the smaller numbers have enabled the ET Trustees to develop a much closer knowledge of each individual registrant’s circumstances than is possible within MFT [the Macfarlane Trust]. It is probably fair to say that ET now gives a more personal service to its beneficiaries than MFT has ever managed.”* Written Statement of Peter Stevens to the Archer Inquiry 23 May 2007 p2 ARCH0002992

653 Written Statement of Richard Titheridge para 7.6 WITN0252001

*just and due ... Our infections have destroyed chances for us in life that others simply take for granted".<sup>654</sup>*

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654 Written Statement of ANON para 29, para 33 WITN4452001

## 6.6 Government Response to Hepatitis C Infections

This chapter details the Government's reluctance over a number of years to provide financial support to those infected with Hepatitis C through NHS treatment. It charts the reasoning which underpinned this reluctance and how pressure from campaigners and MPs helped overcome it. It considers too the significance of events in Scotland and the role those events played in bringing about a change of position in 2003.

### Key Dates

**17 February 1992** Government announcement of financial support for people infected with HIV through transfusions does not extend to Hepatitis C infections.

**December 1994** civil servants within the Department of Health warn that Hepatitis C has moved from being "*a problem on the horizon to a highly political and volatile policy issue*".

**March 1995** the Haemophilia Society launches its campaign for financial help for those infected with Hepatitis C; Gerald Malone agrees to consider the position of those suffering from the worst complications of Hepatitis C.

**June 1995** Ministers agree to maintain the status quo.

**December 1995** John Horam expresses willingness to consider proposals from John Marshall MP.

**October 1996** Department of Health refuses to make any form of payment to those infected with Hepatitis C.

**July 1998** Secretary of State for Health Frank Dobson decides not to set up payment scheme for Hepatitis C.

**2001** Manor House Group, Haemophilia Action UK and Haemophilia Society intensify campaigning.

**October 2001** Scottish Parliament's Health and Community Care Committee calls on the Scottish Executive to provide financial support to all infected with Hepatitis C as a result of NHS treatment in Scotland.

**September 2002** Expert group under Lord Ross recommends payment of compensation for people infected with Hepatitis C through NHS treatment in Scotland.

**November 2002** Alan Milburn tells Malcolm Chisholm that it would be a "*grave mistake*" and "*slippery slope*" to offer support for Hepatitis C.

**29 August 2003** John Reid announces ex-gratia payments: equivalent announcements made in Scotland, Wales and Northern Ireland.

### People

**Virginia Bottomley** Secretary of State for Health (1992 - 1995)

**Malcolm Chisholm** Minister for Health and Community Care, Scotland (2001 - 2003)

**Frank Dobson** Secretary of State for Health (1997 - 1999)

**John Horam** Parliamentary Under-Secretary of State for Health (1995 - 1997)

**Gerald Malone** Minister of State for Health (1994 - 1997)

**Alan Milburn** Secretary of State for Health (1999 - 2003)

**Dr John Reid** Secretary of State for Health (2003 - 2005)

**Tom Sackville** Parliamentary Under-Secretary of State for Health (1992 - 1995)

## The early 1990s

When, in 1992, the Government (with some reluctance) agreed to make ex gratia payments to transfusion and tissue recipients infected with HIV, it did so on the basis that the line would be drawn at this group and that further groups would not receive similar treatment.

For over a decade it maintained that line, refusing to provide any form of financial assistance or ex gratia payment to those infected with Hepatitis C through blood or blood products.

In the early 1990s parliamentarians raised the issue on behalf of constituents, but were met with repeated firm refusals.

Tom Sackville was the Parliamentary Under-Secretary of State for Health between April 1992 and November 1995. His responsibilities included “blood”.<sup>655</sup> His “overall perception” was that “key decisions had been taken by my predecessors, and would continue to be taken by my ministerial superiors<sup>656</sup> and the top officials in the Department; in the case of authorising new expenditure, by the Treasury or even Cabinet.”<sup>657</sup> He “inherited” a clear and established policy that any claims for compensation should be pursued through the courts.<sup>658</sup> When questions were raised by MPs on behalf of constituents or in Parliament, he set out the Government’s position – namely that there were no plans to extend the HIV payment scheme to those infected with Hepatitis C – in his replies.<sup>659</sup>

On 18 January 1994 a minute was provided by Dr Andrzej Rejman and John Canavan to Tom Sackville and to Dr Jeremy Metters (Deputy Chief Medical Officer “DCMO”), which noted that “it is always open to Ministers to make ex gratia or other payments where the special circumstances warrant it”.<sup>660</sup> Arguments for and against special ex gratia payment

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655 Written Statement of Tom Sackville paras 1.3-1.7 WITN5249001

656 His “ministerial superiors” were at this stage Virginia Bottomley, who was Secretary of State for Health until July 1995, and Brian Mawhinney, who was Minister of State for Health until July 1994, when he was succeeded by Gerald Malone.

657 Written Statement of Tom Sackville para 0.5 WITN5249001

658 Written Statement of Tom Sackville para 8.8 WITN5249001. A paper provided to him in August 1992 set out the Government’s resistance to no fault compensation and noted that two recent campaigns had challenged this line. The first was in relation to those infected with HIV/AIDS through blood; the second was those who developed CJD following treatment with human growth hormone. The conclusion was that “We are continuing to hold the line that claims for compensation must be pursued through the courts. There will no doubt be calls from time to time for no fault compensation to be introduced. This will continue to be resisted for the reasons given in this paper.” Memo from John Smith to Dora Pease 11 August 1992 WITN5249023, enclosing a paper Compensation for Medical Accidents WITN5249024

659 Written Statement of Tom Sackville paras 8.10-8.12 WITN5249001. See for example: Letter from Tom Sackville to Elliot Morley 30 October 1992 DHSC0002546\_107, Letter from Tom Sackville to David Porter 2 September 1993 WITN5249039.

660 Memo from Dr Rejman and John Canavan to Dr Metters and Melanie Harper 18 January 1994 p4 DHSC0042296\_065. The central issue in the minute concerned screening of blood donations for rare viral infections, it being recorded that blood transfusion was “inherently unsafe”. Officials raised the issue of ex gratia payments as an alternative to “the introduction of progressively greater numbers of screening tests for all blood donated in the UK”; a scheme of payments was said to be “much less costly than moving towards a policy of screening for every virus for which a test exists”. John Canavan headed the section responsible for policy on blood supply and blood safety within the Department of Health and he worked closely with Dr Rejman who was a senior medical officer. Written Statement of John Canavan para 1.5, para 1.7 WITN7115001



arrangements were outlined and ministers' views were sought on whether the principle of ex gratia payments should be further considered. Following a meeting with Dr Metters, Dr Rejman and John Canavan, the Parliamentary Under-Secretary of State *"did not approve the principle of ex-gratia payments, noting the arguments against such a special arrangement set out in the 18 January 1994 paper."*<sup>661</sup>

A few months later, in June 1994, correspondence was received from David Porter MP asking whether there was any prospect of the Department of Health reconsidering its decision not to offer one-off settlement payments to Hepatitis C sufferers to match the payments made to those infected with HIV. Noting that this was *"A tricky one: if HIV, why not Hepatitis [sic]"*, Tom Sackville asked for advice and a line to take.<sup>662</sup> In response he was advised that the Department's concern was to ring-fence payments to those infected with HIV: *"Each time a concession is made it becomes more difficult to establish a credible ring fence to prevent further movement towards a general no fault scheme for medical accidents."* The justification for making *"special provision"* in the first place had been the double disadvantage of HIV and haemophilia; this was extended to those infected with HIV through transfusion because *"they too were a very special case."* The line to take provided to him was *"no plans to extend the settlement scheme for haemophilia patients with HIV to those who may have been infected with hepatitis."*<sup>663</sup>

In November 1994 *The Independent* newspaper reported that the Haemophilia Society was considering seeking redress from the Department of Health for people infected with Hepatitis C;<sup>664</sup> the article also reported that another 3,000 adults and children who received blood transfusions *"may also have been infected ... but are unaware of their condition."*<sup>665</sup> A background note and line to take maintained the Government's position. The line to take asserted that *"patients who may have been infected with hepatitis C ... will have received the best treatment available in the light of the medical knowledge at the time."*<sup>666</sup>

On 25 November 1994 the Permanent Secretary at the Department of Health, Graham Hart, called a meeting to consider the current policy that the Government would not be making

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661 Written Statement of Tom Sackville para 8.14 WITN5249001, Memo from Melanie Harper to Dr Jeremy Metters and others 4 February 1994 DHSC0042296\_061

662 Memo from Cheryl Cavanagh to Monica Gibson 13 July 1994 WITN5249042

663 Memo from Tom Kelly to Cheryl Cavanagh 15 July 1994 attaching advice in which Hepatitis C was described as much less severe than HIV and without the same *"social consequences of ostracism"*. Memo from Tom Kelly to Cheryl Cavanagh 15 July 1994 p3 WITN5249043

664 The Haemophilia Society itself issued a press release stating that it had no plans to seek compensation from the Government and that its priority was to ensure help and support for those who were unwell as a result of Hepatitis C. The Haemophilia Society *Hepatitis C Infection* 16 November 1994 HSOC0021550

665 *The Independent Contaminated Blood Kills* 12 16 November 1994 WITN5249044

666 Line to take on Settlement Scheme for Haemophilia Patients with HIV DHSC0002501\_104, Memo from David Burrage to G Smith 15 November 1994 DHSC0002501\_102, Background note on Compensation DHSC0002501\_103. A similar briefing and lines to take were provided to the Prime Minister: Memo from David Burrage to Jonathan Mogford and others 16 November 1994 DHSC0003527\_008, Briefing for the Prime Minister on Hepatitis C 16 November 1994 DHSC0003527\_009, and to the Secretary of State for Health: Memo from Tom Kelly to Jonathan Mogford 16 November 1994 DHSC0041152\_216

payments to people with haemophilia infected with Hepatitis C. There was discussion about how this line compared with the scheme for those infected with HIV, the line being taken in relation to those who contracted CJD through human growth hormone, and the scheme for people suffering from vaccine damage. It was agreed to request from officials a reasoned argument as to why the Department of Health regarded the case of those infected with Hepatitis C differently from those infected with HIV in a similar manner, and to pursue a *“positive strategy in respect of haemophiliacs and others who might have been infected with Hepatitis C.”*<sup>667</sup>

In response to this request, on 9 December 1994 Roger Scofield (the head of the Department of Health’s Corporate Affairs Operational Policy Unit) sent an update to senior officials (copied to the private offices of the Chief Medical Officer and the Permanent Secretary) to warn that there had been *“increased interest”* in Hepatitis C and that *“we can expect the campaign for compensation for those infected through NHS treatment to be stepped up over the next few months.”* Hepatitis C had, he said, moved from being *“a problem on the horizon to a highly political and volatile policy issue”*. There was increased media interest (a Panorama programme was due to be screened in January), a campaign for government action, *“a stream of PQs, EDMs and PO cases”*.<sup>668</sup> The pressure was *“building up.”*<sup>669</sup>

Referring to the Permanent Secretary’s meeting on 25 November 1994, the minute recorded that *“On the basis of the experience of HIV it was important to think ahead how this campaign might develop and to decide in advance what positive action might be taken and to develop a robust and defensible line for Ministers.”*<sup>670</sup> As for the proposal for a *“positive strategy in respect of haemophiliacs and others who might have been infected with Hep C”*,<sup>671</sup> what was contemplated by officials was a package of initiatives that the Department of Health could take *“short of an ex gratia payment scheme.”* In the meantime ministers had been advised to take the line that there were no plans to make payments.<sup>672</sup>

This was followed by a submission to the Parliamentary Under-Secretary of State for Health on 22 December 1994. The submission set out the Department’s understanding that about 3,000 people with bleeding disorders and a further 3,000 who had transfusions before September 1991 were believed to have been infected with Hepatitis C as a result of NHS treatment. The principal focus of the submission was whether a lookback exercise should be undertaken, but it was also explained that it had been known for at least five years that some people would have been infected through NHS treatment and that the Department had *“expected at any time a campaign to be mounted along the lines of that*

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667 Memo from Rosamund Roughton to Roger Scofield 25 November 1994 p2 DHSC0002548\_139

668 A reference to parliamentary questions, Early Day Motions and Private Office cases.

669 Memo from Roger Scofield to Dr Metters 9 December 1994 p1 WITN5249046

670 The minute also noted that the Department of Health’s solicitors still needed to explore whether the Government had been negligent but it was *“sensible in the meantime to assume it had not been.”* Memo from Roger Scofield to Dr Metters 9 December 1994 p2 WITN5249046

671 A number of potential actions were identified, including conducting a lookback and ensuring that all affected had proper access to treatment facilities.

672 Memo from Roger Scofield to Dr Metters 9 December 1994 pp3-4 WITN5249046

for HIV".<sup>673</sup> Notably the submission recorded that counsel's advice had not yet been sought on whether any case existed for negligence: rather "*Officials have taken the line throughout that everything has been done that could have been and that they acted on the advice of the Advisory Committee on the Virological Safety of Blood ... which was set up specifically in order to provide Ministers with advice on blood safety.*"<sup>674</sup>

In January 1995 a reply to an MP's query about the possibility of compensation reiterated that the Government had never accepted the case for no fault compensation "*for medical accidents.*"<sup>675</sup> A briefing note for a parliamentary written answer to be given on 30 January by Baroness Julia Cumberlege, the Parliamentary Under-Secretary of State for Health in the House of Lords, confirmed further that the Government was concerned by the potential costs of a Hepatitis C payment scheme.<sup>676</sup>

An email from Roger Scofield on 8 February 1995 to Dr Rejman and others, attaching a draft paper which attempted to sketch out a payment scheme for Hepatitis C "*on a contingency basis*", observed that "*Ministers have clearly got the wind up and don't feel that we have a good defence.*" It was acknowledged that "*the Government might have to reconsider its position if determined cross party support were to emerge, especially if this was fuelled by a major Press campaign.*"<sup>677</sup> On 10 February he wrote to the Permanent Secretary, noting that ministers had "*publicly stated that they are against making any payments to those infected but are concerned that the arguments we have given them for defending such a policy are unconvincing.*"<sup>678</sup> An official within the Department of Health's finance division minuted the Permanent Secretary's Private Office in response to Roger Scofield's submission, stating that past experience was that obtaining Treasury agreement was not an easy matter and was somewhat time consuming.<sup>679</sup>

On 6 March 1995 the Permanent Secretary held a meeting with officials to discuss whether it would be appropriate to prepare options for some kind of payment scheme for those infected with Hepatitis C as a result of NHS treatment. The note of the meeting records that there was considerable political pressure against the current line. The conclusion was that there were three options "*worth considering as possibilities*": maintain the status quo, set up a Hepatitis C payment scheme along the lines of Roger Scofield's submission, or set up

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673 In a message commenting on a draft of this submission, the director of Corporate Affairs, John Shaw, wrote "*In various places ... we say that we have not yet done various things and this reads oddly against the comment ... that we have known about this issue for five years and have been expecting a campaign of this sort at any time. And yet we are caught unawares apparently. We either need to explain this apparent contradiction or to make our lack of preparedness less obvious (if we can do so without telling fibs).*" Memo from John Shaw to Roger Scofield 22 December 1994 p1 DHSC0032203\_151

674 Memo from Roger Scofield to Andy Hollebon 22 December 1994 pp1-2 DHSC0032208\_149

675 Written Statement of Tom Sackville para 8.26 WITN5249001, Letter from Tom Sackville to Ann Winterton WITN5249047

676 Written Statement of Tom Sackville para 8.31 WITN5249001, House of Lords oral questions 27 January 1995 p4 NHBT0005768\_002

677 Email from Roger Scofield to Dr Rejman and others 8 February 1995 p2 DHSC0032208\_071, Memo from Roger Scofield to Charles Blake 10 February 1995 pp1-2 DHSC0032203\_070

678 Memo from Roger Scofield to Rosamund Roughton 10 February 1995 p1 WITN7112036

679 Memo from Mike Brownlee to Rosamund Roughton February 1995 WITN7112040

a more general scheme, possibly for those infected with diseases through blood and blood products, or through materials of human origin.<sup>680</sup>

In practice the status quo was maintained for the next eight years.

## The Haemophilia Society's campaign

On 14 March 1995 the Haemophilia Society launched its campaign for financial help for those infected with Hepatitis C. Reporting that over 40 people with haemophilia had died, a statement from the Reverend Tanner explained that:

*“Over 3,000 people with haemophilia have been infected with this potentially life-threatening virus through treatment with clotting factor concentrates before 1986 ... People with haemophilia were infected with the hepatitis C virus through contaminated blood products ... Many were not told that there was a risk of hepatitis when they were given the treatment. They were infected in exactly the same way as over 1,200 people with haemophilia contracted the HIV virus – through treatment with contaminated blood products. Yet while those infected with HIV receive financial help from the government those with HCV receive nothing ... The government have said that they do not intend to provide financial help for people infected with hepatitis C. I would ask the government how many more should die before they decide that HCV is an immediate threat to people with haemophilia ... parliamentarians are taking the subject seriously. I would like the government to take it seriously as well and would make the plea for them to accept their moral responsibility and act swiftly and decisively to provide help for people with haemophilia infected with this dreadful disease.”<sup>681</sup>*

On 30 March 1995 John Marshall MP, who had been instrumental in the efforts to obtain assistance for transfusion recipients infected with HIV, and who had been raising the matter in Parliament, met the Minister of State for Health, Gerald Malone, to discuss this question. This intervention plainly had some impact upon the Minister, because he agreed that the Department of Health should give very careful consideration to whether those suffering from the worst complications of Hepatitis C might be granted ex gratia payments.<sup>682</sup>

This willingness on the part of the Minister of State simply to **consider** John Marshall's proposal gave rise to consternation in the Department.

Roger Scofield wrote to colleagues the same day as follows:

*“You will wish to see that [the Minister of Health] has come out in favour of making payments to haemophiliacs and others infected by HCV. He has yet to convince*

680 The attendees included Dr Metters and Dr Rejman, Roger Scofield, Mike Brownlee from the Finance Division and Charles Blake from the Department of Health's Solicitor's Office. Note of meeting regarding Hepatitis C 6 March 1995 WITN7112041

681 Haemophilia Society Press Release *Haemophilia Society Launches Campaign as Hepatitis C Death Toll Mounts* 14 March 1995 pp1-2 HSOC0014049

682 Memo from David Abrahams to Roger Scofield 30 March 1995 DHSC0002548\_009

*his Ministerial colleagues. I understand that Dr Metters has advised Perm Sec to go for a meeting with Minister rather tahn [sic] try and cover it in the margins of [the Top of the Office meeting]. This might mean a meeting next week rather than this. Either way I shall move swiftly to get papers round for comment.”*<sup>683</sup>

The Secretary of State, Virginia Bottomley, in her oral evidence to the Inquiry described how, in light of the report on Gerald Malone’s meeting with John Marshall, “*alarm bells started to ring. Mr Sackville, the responsible minister, although junior minister, evidently thought ‘This is going to end in tears’, and the Permanent Secretary ... sort of canters over the horizon to say ‘I would urge great caution’, or, you know, ‘You’ll never find a more comfortable ringfence’.*” She described Gerald Malone as having “overspoken” and having “got a bit carried away”.<sup>684</sup>

In early April 1995 a paper was produced in response to a request from Gerald Malone. Roger Scofield cautioned that such a scheme was, “the exact opposite of the position that the Government generally and Health Ministers in particular have taken to date.” The terms of the advice sought to steer the Minister firmly away from any such scheme. The Government’s opposition to no-fault compensation was set out; it was suggested that those infected might access “*the full range of health, social and security services provided by the government*” as a “*safety net*”; it was positively asserted that “*Those patients who were infected were given the best treatment available at the time*”; special factors were said to apply to the HIV settlement; the Treasury would strongly resist a claim for funding and thus “*any money spent on a hardship scheme would probably be at the direct expense of direct health care*”; and the Minister was warned that there would need to be a “*clear policy justification for establishing a special payments scheme ... this would need to be argued, initially with the Treasury and probably the cabinet as a whole, as well as be defensible before the PAC*”<sup>685</sup> if such payments were challenged.”<sup>686</sup>

The Permanent Secretary, Graham Hart, was also highly doubtful about a scheme, suggesting that there would be “*great resistance to any weakening of the line*”, that any “*concession towards Hepatitis C victims would be very difficult*”, and that “*Ministers will certainly wish to discuss this very fully with officials before reaching a view.*”<sup>687</sup> Ahead of a ministerial meeting to discuss the position, Graham Hart wrote to Gerald Malone on 12 April 1995:

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683 Email from Roger Scofield to Dave Burrage and others 30 March 1995 p2 DHSC0002610\_006. The Top of the Office meeting was held once a week and attended by the five Ministers, Permanent Secretary, Chief Medical Officer, Chief Nursing Officer, NHS Chief Executive and Chief Inspector of Social Services. Written Statement of Virginia Bottomley para 2.1(8) WITN5289001

684 Baroness Virginia Bottomley Transcript 28 June 2022 pp144-146, p155 INQY1000216

685 The Public Accounts Committee.

686 Memo from Roger Scofield to David Abrahams 6 April 1995 pp1-3 MHRA0025171. Emphasis in original.

687 Memo from Graham Hart to Andy Taylor 6 April 1995 DHSC0042937\_121. Tom Sackville thought the Permanent Secretary’s position looked “*pretty decisive*” and that it would be “*important that Secretary of State is well briefed for a Cabinet discussion*.” Memo from Andy Hollebton to John Holden 11 April 1995 DHSC0042937\_120. In his written statement to the Inquiry he stressed that there was no lack of sympathy for Hepatitis C sufferers “*but my colleagues and I were acutely aware of the limited resources available to the NHS and the likely strong opposition by the Treasury to any scheme of ex gratia payments.*” Written Statement of Tom Sackville para 8.42 WITN5249001

*“I do not need to repeat the difficulties that would arise over any decision to concede on payments to those infected with Hepatitis C by blood transfusions or blood products. Those are difficulties of principle as well as practice – and I find them pretty compelling. I recognize, of course, that the political pressures could become too great but I think the prospects of persuading other Departments, especially the Treasury, that we had to move now are not at all good.”*

He added that it would be useful to have a full discussion of the pros and cons before any decision was reached and that in the meantime *“we must avoid giving any hints to anyone that our line could weaken. That could be fatal.”*<sup>688</sup>

Baroness Cumberlege was also firmly opposed, writing on 11 April 1995 that it would be *“a great mistake to concede payments for Hepatitis C victims. It was a mistake to concede the HIV victims but the scheme was at least clearly defined ... It is too easy to slip into no fault compensation which would be financially and principally disastrous, not only for the NHS but to other areas of Government.”*<sup>689</sup>

Whether as a result of the firm advice from the Permanent Secretary, or the opposition of ministerial colleagues, or otherwise, Gerald Malone changed his mind. On 1 May 1995 he wrote that he would *“firmly and enthusiastically support a strategy to resist compensation payments”* and that a *“logical and defensible distinction can be drawn between HIV sufferers and Hepatitis C sufferers.”* He added that if payments were to be resisted it would be *“catastrophic to cave in to any subsequent pressure”* and that *“Number 10 must be taken along at all stages and alerted both to the likely vigour of the campaign and to the fact that the PM could be faced with a powerful deputation at what might be a difficult moment.”*<sup>690</sup> Virginia Bottomley agreed, commenting that *“there will always be new examples”* and that a consistent line must be held. She asked that the Department *“establish the views of the territorials”* and that the senior departmental official *“talk Carolyn Fairbairn from No 10 through the issues.”*<sup>691</sup>

In accordance with the Secretary of State’s request, the views of officials from Scotland, Wales and Northern Ireland were sought,<sup>692</sup> and Number 10 was alerted to the issue.<sup>693</sup> A meeting of ministers was arranged for 7 June 1995. The views of the *“territorials”* on compensation

688 Memo from Graham Hart to Andy Taylor 12 April 1995 DHSC0042937\_119

689 Memo from Sharon Wallace to John Holden 11 April 1995 WITN7112045. Emphasis in original.

690 The *“difficult moment”* which he had in mind was *“around Party Conference time or at the time of a possible challenge to his leadership.”* Memo from Gerald Malone to Graham Hart 1 May 1995 WITN5249050

691 See the handwritten note from the Secretary of State: Memo from Gerald Malone to Graham Hart 1 May 1995 WITN5249050, Memo from Alastair Thomas to Andy Taylor 5 May 1995 WITN5249051. Carolyn Fairbairn worked in the Number 10 Policy Unit.

692 Letter from Roger Scofield to David Hogg 9 May 1995 DHSC0006946\_010. The letter was copied to the Welsh Office and the Northern Ireland Office. In a memo of 9 May 1995 to Dr Metters, Roger Scofield said he had amended his original submission to Carolyn Fairbairn and *“the territorials”* slightly *“to put it in such a way that Ministers do not appear to be at odds with one another; nor do I wish to spell out their concerns on paper.”* He also intended to speak to them. Memo from Roger Scofield to Dr Metters 9 May 1995 DHSC0006327\_007

693 Letter from Roger Scofield to Carolyn Fairbairn 9 May 1995 DHSC0006946\_009

for those infected with Hepatitis C through blood transfusion and blood products were set out in an update in advance of the meeting. The view of officials in Scotland was that *“while the ‘no-compensation’ position is becoming increasingly untenable, proposals to link payments to social needs and the degree of harm suffered would be difficult to establish and the (clinical) judgements required would make it costly and complex to administer.”* Legal advisers in Wales were of the view that *“it would be difficult to sustain rejection of claims for compensation on the grounds of a distinction between those infected with HIV and HCV.”* They agreed that clinical assessment of the effect of Hepatitis C on individuals would be difficult due to its variability. In Northern Ireland, officials’ view was that *“it is difficult from point of view of equity to resist comparisons with HIV compensation.”* All expressed a view about costs and indicated that the views of ministers had not yet been sought.<sup>694</sup>

Notwithstanding these views from *“the territorials”* as to the difficulties of reliance on a distinction between HIV and Hepatitis C, all those present at the meeting on 7 June 1995 – which included Gerald Malone, Tom Sackville, Dr Metters, Graham Hart and Carolyn Fairbairn – *“were agreed that it would be desirable to maintain the status quo and not extend the principle of no-fault compensation either to those infected with Hepatitis C or CJD. The precedent of payments to those infected with HIV/AIDS through blood and blood products was not helpful in this context but it was agreed that a justifiable distinction could be drawn between HIV/AIDS and other viruses.”*<sup>695</sup>

The following day, 8 June 1995, Alf Morris MP tabled an Early Day Motion calling for financial assistance, to which the Department of Health’s line to take remained *“We have great sympathy for those affected, but have no plans to make special payments.”*<sup>696</sup> A briefing for the Prime Minister dated 9 June 1995 reiterated both the lack of plans to provide compensation and that patients received *“the best treatment available in the light of medical knowledge at the time.”*<sup>697</sup>

John Marshall therefore turned his attention to Number 10. He asked to bring a deputation to see the Prime Minister, John Major, to discuss the position of people infected with Hepatitis C from blood products.<sup>698</sup> The advice from the Department of Health was that it

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694 Memo from Paul Pudlo to David Abrahams (assistant private secretary to the Minister of State for Health) 5 June 1995 DHSC0004428\_152. The meeting decided that further work on legal vulnerability, in particular in relation to consumer protection legislation, was required before the question of ex gratia payments could be decided. Email from Paul Pudlo to Roger Scofield 7 June 1995 DHSC0042937\_103

695 Memo from David Abrahams to Benjamin Dyson 7 June 1995 p2 DHSC0003552\_155. The discussion at the meeting had centred on whether the Department of Health would be able to successfully defend a negligence claim. It was agreed at the meeting that the Department of Health’s case was weakest in connection with those infected with Hepatitis C in the period 1990-91 because: a test was in existence, it was being used in a number of countries, and some experts were urging the introduction of testing, although the expert committee advising ministers (a reference to the Advisory Committee on the Virological Safety of Blood) did not consider it sufficiently reliable. Given this acknowledgement, the Department of Health’s later line to take asserting that testing had been introduced as soon as available is all the more astonishing and concerning: see the chapter on *Lines to Take*.

696 Early Day Motion on Haemophilia and Hepatitis C p1 DHSC0006774\_060

697 Hepatitis C briefing for the Prime Minister 9 June 1995 p1 DHSC0006600\_080

698 Letter from John Marshall to John Major 24 May 1995 DHSC0032176\_129. As well as pointing to the plight of those who had been infected and that *“Some of them have died already and others will do*

would not be appropriate for the Prime Minister to meet this delegation, health ministers having recently met and decided to “*maintain the current line*.”<sup>699</sup> That “*current line*” was the expression of “*great sympathy*”, followed by the Government not accepting “*that there has been any negligence*” and an assertion that patients infected with Hepatitis C “*received the best treatment available in the light of medical knowledge at the time*.”<sup>700</sup>

Stephen Dorrell, who became Secretary of State for Health on 5 July 1995 (succeeding Virginia Bottomley), gave evidence before the Health Select Committee on 19 July 1995, where he was questioned by John Marshall. His position, which he believed “*very strongly to be true*”, was that “*any patient who undertakes a course of medicine must accept that there is a risk attached to modern medicine and in cases where a patient is damaged but without any fault, I do not believe that it is a sensible use of NHS resources to provide compensation in those cases ... Where there is no fault, I am not in favour of compensation as a principle*.” He acknowledged that there was an “*illogicality*” between the position of those with HIV and those with Hepatitis C, but asserted that “*the haemophiliac who contracted AIDS as a result of blood transfusion was provided with compensation in contravention of the principle which I enunciated*.”<sup>701</sup>

On 31 July 1995 the Secretary of State wrote to Sir Edward Heath MP, who had raised the Haemophilia Society’s campaign on behalf of a constituent, stating that there were no plans to make payments to those infected with Hepatitis C.<sup>702</sup> This letter both reflected the Department’s established position and provided Stephen Dorrell “*with an opportunity to clarify my own view early in my tenure as Secretary of State*.”<sup>703</sup>

John Marshall and other MPs renewed their request to the Prime Minister to receive a small delegation in September 1995.<sup>704</sup> The Prime Minister was “*unconvinced*” and a briefing was sought from the Department of Health, “*to include a summary of the line he might take in such a meeting*.”<sup>705</sup> The briefing provided expressed confidence that patients received “*the*

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so”, he made “*the purely political point that a decision to help this unfortunate group might improve our image at a relatively low cost*.”

699 Letter from Mike Yates to Mark Adams 10 July 1995 DHSC0032176\_126. Hepatitis C was said to be different to HIV. “*Many people infected with hepatitis C may enjoy a long period without any symptoms appearing. 50 per cent of sufferers may progress to chronic hepatitis with varying degrees of good and ill health. Perhaps 20 per cent of infected patients will develop cirrhosis, a progressive destruction of the liver, that may take 20 to 30 years. The majority of those years will be trouble free in terms of ill health and only a small percentage will actually die of liver disease*.”

700 See for example: Letter from Baroness Cumberlege to John Marshall 19 January 1995 p1 DHSC0004478\_024

701 Extract from Health Select Committee proceedings 19 July 1995 pp1-2 DHSC0042937\_094

702 Letter from Stephen Dorrell to Sir Edward Heath 31 July 1995 DHSC0032176\_003

703 Written Statement of Stephen Dorrell para 2.12 WITN5290001

704 Letter from John Marshall and others to John Major 30 September 1995 CABO0000044\_040. The advice from the Prime Minister’s Private Secretary, noting that the Department of Health had “*currently drawn a firm line between the two viruses*”, was that the Prime Minister should “*give the group a hearing*”. Memo from Mark Adams to the Prime Minister 25 October 1995 CABO0000044\_041. Following the tabling of an Early Day Motion signed by 233 MPs from all parties, on 16 November 1995 Mark Adams again advised the Prime Minister to meet the delegation. Memo from Mark Adams to the Prime Minister 16 November 1995 CABO0000044\_044

705 Letter from Mark Adams to John Holden 20 November 1995 DHSC0004498\_143



*best treatment available in the light of medical knowledge at the time*” and characterised the MPs’ request as being for compensation “*for patients where, tragic though their circumstances are, no fault and no negligence on the part of the NHS has been proved.*”<sup>706</sup> In January 1996 the Prime Minister declined to meet with John Marshall: he wrote that the “*compensation*” previously provided “*reflected the very special nature of the HIV virus*” and there was nothing to be gained by further discussion.<sup>707</sup>

## Another junior minister tries to reconsider the policy

In December 1995 the Haemophilia Society had published a report which it had commissioned to examine the needs of people with haemophilia and Hepatitis C.<sup>708</sup> A note prepared for the Secretary of State and for John Horam (later Lord Horam), the new Parliamentary Under-Secretary of State for Health, suggested that it was reasonable to suppose the published evidence was “*emotively and selectively used*”. Some criticisms were said to be of failings of clinical management by doctors and other healthcare professionals. It was further observed that from the early 1970s onwards it had been appreciated that haemophilia patients were at risk (“*and indeed some were becoming jaundiced following treatment*”). This was said

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706 Briefing for the Prime Minister on Hepatitis C 21 November 1995 p1 DHSC0042937\_057. Stephen Dorrell told the Inquiry in his written statement that these briefings to the Prime Minister were part of the regular process of ensuring that the PM was briefed on current issues ahead of his twice weekly appearances at Prime Minister’s Questions, and that they were “*therefore the subject of regular scrutiny [by] both ministers and senior officials.*” Written Statement of Stephen Dorrell para 2.21 WITN5290001. This being the case, it is all the more surprising that the briefings included the best treatment available line.

707 Letter from John Major to John Marshall 26 January 1996 p2 CABO0000007\_001

708 Hepatitis C Impact Study Interim Report 1 December 1995 HSOC0002726\_002. On 19 December 1995 the Secretary of State met Roy Hattersley MP and the Manor House Group, at which the delay in informing people that they had been infected with Hepatitis C was raised as an issue. A report on the meeting by Paul Pudlo provides some insight into the stance of officials. The report rather dismissively described much of the meeting as “*taken up with a series of emotive accounts of individual plight to which SofS listened patiently.*” The Secretary of State was described as surprised at allegations that some patients had been kept in the dark about Hepatitis C infection for some time after it had been diagnosed: “*We explained that what a patient is told is a matter for local judgement and that there may be reasons for not informing immediately – eg no treatment available – unreliable test.*” The Secretary of State asked for David Tonkin’s case to be investigated. Memo from Paul Pudlo to Kevin Guinness 19 December 1995 WITN5290017, Memo from Paul Pudlo to Andrew Griffiths 19 December 1995 DHSC0003971\_075. A letter was then sent to Roy Hattersley MP on 7 February 1996 stating that “*Having investigated, I understand the decision about when to inform [ANON] was made on purely clinical grounds. There is no evidence whatever of administrative error or oversight.*” Letter from Stephen Dorrell to Roy Hattersley 7 February 1996 HSOC0014327. It is unclear what investigation was undertaken or what information was provided to the Secretary of State, but the evidence available to the Inquiry indicates that David Tonkin was indeed tested for Hepatitis C in 1992 and not informed of the diagnosis until 1994. That this appears to the Department of Health to be perfectly acceptable is surprising.

to be “*an accepted side-effect at that time taking into account the benefit.*”<sup>709</sup> By way of comment, the note seems aimed at disparaging the report. It does so unfairly.<sup>710</sup>

At an adjournment debate on 13 December 1995, John Horam, whilst asserting that “*The patients we are now discussing received the best treatment available in the light of medical knowledge at the time*”,<sup>711</sup> indicated that he would like to read the Haemophilia Society’s report thoroughly and that he would be interested to hear details of the “*relatively modest and restricted proposal*” made by John Marshall during the debate.<sup>712</sup>

Just as his predecessor Gerald Malone’s willingness to consider the possibility of a shift in policy had caused consternation within government, so too did John Horam’s.

A Treasury official wrote to the Department of Health, expressing concern about what had been said: “*The Government has a firm and agreed policy on such issues. Consistent with that policy, and for the avoidance of doubt, I should indicate that the Treasury would be strongly opposed to what Mr Horam termed ‘the relatively modest and restricted proposal’ made by Mr John Marshal [sic] MP.*”<sup>713</sup> This letter was seen by John Horam for the first time when preparing his statement for the Inquiry: he expressed concern at the letter and surprise that it was not drawn to his attention by officials within the Department of Health.<sup>714</sup>

John Horam’s proposal of a modest amendment to the Department’s standard line, to add the words “*at present*” to the words “*we have no plans to make special payments*”, led to an expression of alarm by civil servants: “*we fear that if we were to qualify the existing line in correspondence as suggested, it would be taken as indicating a weakening of the Government’s position, and imply that compensation is being considered and further*

709 Memo from Paul Pudlo to Marguerite Weatherseed 1 December 1995 DHSC0042937\_071, The Haemophilia Society *Hep C Impact Study* DHSC0042937\_072. John Horam, now Lord Horam, became Parliamentary Under-Secretary of State for Health in November 1995. Whilst the Department of Health was quick to criticise the sample and methodology of the report commissioned by the Haemophilia Society, it should be borne in mind that at no point in its decision-making did the Department of Health commission or undertake any research of its own.

710 For instance, the second paragraph begins: “*The sample is not sufficiently large nor the methodology sufficiently scientific to allow valid conclusions that are representative to be drawn. For example the sample is unrepresentative in that well in excess of 20% are suffering from liver damage – whereas both the report and officials accept that a proportion of only 10-20% would be expected.*” However, the first paragraph both accepts that some 3,100 people with haemophilia have been infected with Hepatitis C as a result of treatment with infected blood products and that “*Overall the effects described of Hep C on peoples’ lives is not in dispute*” – in short, that these descriptions are indeed representative. Finally, it conflates being jaundiced with knowledge of the long-term effects of non-A non-B Hepatitis, as to which it is clear beyond doubt from the evidence the Inquiry has heard that the majority of patients were wrongly assured that non-A non-B Hepatitis was an infection with little or no potential clinical consequences.

711 This was based on the draft speech prepared by officials. Assistance to individuals who are Haemophiliacs and have Hepatitis C p8 DHSC0006774\_066. In his evidence to the Inquiry Lord Horam confirmed that this was information provided to him by officials and that treatment with cryoprecipitate, and its role in improving life expectancy, was never raised with him by officials. Lord John Horam Transcript 29 June 2022 p34 INQY1000217

712 House of Commons debate on Haemophiliacs 13 December 1995 pp3-5 HSOC0002072. Lord Horam told this Inquiry that on reading the report he was “*struck by the awful consequences of the condition.*” Lord John Horam Transcript 29 June 2022 p26 INQY1000217

713 Letter from Joseph Grice to Charles Dobson 18 December 1995 DHSC0042937\_036

714 Lord John Horam Transcript 29 June 2022 p42 INQY1000217

*continued pressure would lead to concessions.*” It was suggested that the Minister discuss the proposed additional wording with the Secretary of State.<sup>715</sup>

It is clear that in making this suggestion officials were hoping that the Secretary of State would curtail John Horam’s willingness to look afresh at this issue. No doubt with the same aim in mind, the minute was forwarded to the Permanent Secretary with the following note:

*“The Permanent Secretary may wish to be aware of the attached minute. I mentioned to him the other day that PS (H) [Parliamentary Under-Secretary of State for Health] was clearly not happy with the firm line Ministers have taken up to now on compensation for haemophiliacs infected with hepatitis C. It is quite clear that he is trying to change the line, little by little. He has had plenty of briefing (written and oral) on the subject, but his sympathy for those concerned is clearly uppermost in his mind. Cost comes second – hence his readiness to consider proposals for a scheme limited to those who have actually developed chronic illness, rather than extending to all who have been infected.”*<sup>716</sup>

On 12 January 1996 John Horam requested a submission setting out costed options for compensation. His Private Office explained that:

*“PS(H) has been giving further thought to the issue of awarding compensation to haemophiliacs who contracted hepatitis C before routine screening of blood products was introduced. He is well aware of our current position on this issue and the reasons for this. However, against a background of mounting political pressure, he would like to explore the options for offering compensation, if only to assure himself that we have done all that is feasible.”*<sup>717</sup>

In the meantime, but without John Horam’s knowledge, the Permanent Secretary, Graham Hart, expressed the view that:

*“if pressure continues, we shall eventually be forced to concede. It would be nice to do so in an orderly manner, but, in practice, the Treasury would be unlikely to budge until such time as the political situation became so untenable that the Prime Minister decreed that something had to be done. For the time being, therefore, we should continue to hold the line firmly ... it would probably be wise*

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715 Memo from Ann Towner to Paul Pudlo and Marguerite Weatherseed 20 December 1995 DHSC0004498\_051. A reply on behalf of the Minister explained that he *“very much accepts the Department’s stance on this issue, but does not want to give the impression that he is deaf to the concerns of the haemophiliac community.”* Civil servants were asked to propose an alternative form of words which would convey that he wanted to read the Haemophilia Society’s report carefully. Memo from Marguerite Weatherseed to Paul Pudlo 21 December 1995 DHSC0004498\_045

716 Email from Kevin Guinness to Ann Towner 20 December 1995 DHSC0004498\_188. The message added that the Secretary of State had met a group of people with haemophilia, led by Roy Hattersley MP, the previous day *“and made no concessions”*.

717 Memo from Marguerite Weatherseed to Kevin Guinness 12 January 1996 DHSC0003883\_123

*to undertake some contingency work on the sort of scheme favoured by John Marshall so that we can move quickly if necessary.”*<sup>718</sup>

Lord Horam told the Inquiry that he did not see this minute at the time, was surprised to read that the Permanent Secretary’s view was that the Department of Health would eventually be forced to concede and was concerned that this information was not shared with him at the time.<sup>719</sup>

That officials believed that John Horam was stepping out of line is also apparent from a minute of 9 January 1996:

*“The new PS(H) John Horam wishes to appear is [sic] sympathetic to the situation of haemophiliacs who contracted Hepatitis C and open to receiving and considering any information put forward. However no commitment to making any such payments has been made. Officials fully understand the financial and precedent implications of introducing even some form of limited ‘compensation scheme’ and will continue to make these clear to Minister as opportunity arises, as they did when briefing for the debate in question ... Officials will of course continue to keep a watch on the relevant correspondence etc. And of course PS(H) cannot alter the Department’s policy without agreement of SoS who – recent correspondence suggests – retains a firm line.”*<sup>720</sup>

On 19 January Kevin Guinness asked his colleague preparing a first draft of the options paper requested by John Horam to include reference to it being a “*Slippery Slope*” and to stress that any payments “*would have to come from less money being available for patient care.*”<sup>721</sup>

On 9 February 1996 the submission requested by John Horam setting out options for compensation of people with haemophilia with Hepatitis C was provided. It recorded that people infected through blood transfusion “*would have as good cause as haemophiliacs for access to a compensation scheme*” and that in the view of officials “*if anything*” the case for people infected through transfusion “*is stronger because some were infected after tests were known to exist.*”<sup>722</sup> The submission clearly sought to steer the minister away

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718 Memo from Kevin Guinness to Dr Rejman 8 January 1996 (incorrectly dated 1995) DHSC0042937\_032. Kevin Guinness was now leading on the issue for the Corporate Affairs Operational Unit. In his statement to the Inquiry Sir Graham Hart explained his views as being that “*the position which ministers had taken was justified and defensible but that the pressure to change it, notably from victims, members of Parliament and some parts of the media, was growing in strength. If the pressure on ministers continued to build up, it could reach the point at which they found their position no longer tenable: I did not think it was inevitable, or imminent.*” Emphasis in original. Written Statement of Sir Graham Hart para 3.60 WITN7112001

719 Lord John Horam Transcript 29 June 2022 pp53-54 INQY1000217

720 Memo from Ann Towner to Kevin Guinness and Karen Marshden 9 January 1996 DHSC0042937\_035

721 Memo from Kevin Guinness to Paul Pudlo 19 January 1996 DHSC0002550\_064

722 Submission from Kevin Guinness to Marguerite Weatherseed 9 February 1996 p1, p8 SCGV0000166\_015. It is difficult to square the recognition that some were infected after tests were available with the Department of Health’s subsequent line to take that tests had been introduced as soon as available.

from support for a scheme.<sup>723</sup> In his oral evidence to the Inquiry Lord Horam expressed a degree of puzzlement at this document, describing it as “*overkill*”. He had not been trying to overturn the Government’s entire stance on no fault compensation, but to examine whether a more modest scheme could be introduced, focusing on those with cirrhosis.<sup>724</sup>

On 20 February the Haemophilia Society issued the final version of the report which it had commissioned on Hepatitis C and haemophilia.<sup>725</sup> Officials’ line to take in response to it remained that there were no plans to make payments, “*these patients*” having received the best treatment available in the light of medical knowledge at the time. It was however acknowledged that John Horam would be meeting the Haemophilia Society the following month.<sup>726</sup>

Having considered the submission of 9 February, John Horam was still keen to consider the options and to keep an open mind in advance of his meeting with the Haemophilia Society. He asked for more information about the likely costs of a scheme limited to those who developed cirrhosis.<sup>727</sup> The Permanent Secretary counselled “*extreme caution*”, telling the Minister that “*The unfortunate truth is that this is a very slippery slope. Our present stance is uncomfortable, but any movement from it, however slight, is likely to start something we won’t be able to stop.*”<sup>728</sup>

The meeting between the Minister and the Haemophilia Society took place on 26 March 1996. The Haemophilia Society sought to emphasise “*the social, psychological, economic and medical impact on individuals and their families*”: it believed that there was a “*clear moral case*” for financial recompense.<sup>729</sup> Following the meeting the Haemophilia Society provided further information about their proposals to the Department of Health.<sup>730</sup>

In Stephen Dorrell’s written evidence to the Inquiry, he suggested that during the period when John Horam “*devoted considerable time and energy to reviewing options for dealing with these issues*”, the records showed that the civil servants, including the Permanent

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723 See the conclusions. Submission from Kevin Guinness to Marguerite Weatherseed 9 February 1996 p12 SCGV000166\_015. As Lord Horam observed in his written statement to the Inquiry, it was fair to say that officials were giving him “*strong warnings*”. Written Statement of Lord John Horam para 2.34 WITN5294001

724 Lord John Horam Transcript 29 June 2022 pp73-76 INQY1000217

725 Haemophilia and Hepatitis C Research Report January 1996 HSOC0002726\_001

726 Memo from Kevin Guinness to Richard Billinge 20 February 1996 p1 DHSC0004469\_007

727 Memo from Marguerite Weatherseed to Kevin Guinness 28 February 1996 p1 DHSC0003883\_101. The further information was provided on 11 March 1996. Letter from Kevin Guinness to John Adey 11 March 1996 SCGV0000166\_005

728 Memo from Benjamin Dyson to Marguerite Weatherseed 29 February 1996 DHSC0003883\_100. John Horam agreed to bear these points in mind. Memo from Marguerite Weatherseed to Benjamin Dyson 5 March 1996 DHSC0003883\_099

729 Briefing for meeting between representatives of the Haemophilia Society and John Horam 25 March 1996 p1 HSOC0014417. Some elements of the scheme which they advocated – a lump sum across the board payment to all infected and a second lump sum triggered by changed circumstances – did, over seven years later, become part of the Skipton scheme when the Government finally changed its policy. The briefing for the Minister noted that the Haemophilia Society had been “*encouraged by what they perceive to be a softening in Ministers’ position*”. Policy on Compensation 28 February 1996 p1 DHSC0002533\_007

730 Memo from Paul Pudlo to Marguerite Weatherseed 4 April 1996 DHSC0042289\_176

Secretary, “engaged with ministers for a serious review of the options available to the government”.<sup>731</sup> I do not agree that the records show the Department engaging in a serious review of the options. Rather they show a Department determined to steer John Horam away from even a modest adjustment to the existing line.

In late April 1996 the Secretary of State met John Marshall and explained that “*whilst he was very sympathetic towards haemophiliacs with Hepatitis C, he did not consider that no-fault compensation of £40m would be an appropriate use of health resources.*”<sup>732</sup>

A briefing note prepared in advance of that meeting included a reference to Stephen Dorrell’s evidence to the Health Committee in July 1995 which “*acknowledged that payment to the HIV group was illogical.*”<sup>733</sup> This led Charles Dobson to write to colleagues on 23 April 1996 noting that the precedent set by the HIV scheme was “*indeed a problem, but I didn’t think we had ever gone so far in public!*” He suggested:

*“If ministers are having serious worries about the precedents caused by the HIV scheme there is an alternative handling option ... that is to admit that our legal case in the HIV litigation was not 100% watertight. In other words, we could (at this distance in time) suggest that the government agreed to the HIV scheme not because there was anything special about the plight of haemophiliacs, but on a straight calculation of the balance of risk that the court would in fact have found it negligent if the case had come to trial. This preserves the “purity” of the government’s stance on no-fault compensation”*<sup>734</sup>

It is unclear whether this was a suggestion that the Government should say that the reasons for the establishment of the HIV scheme were something other than in fact they were; or whether Charles Dobson was saying that this was the real reason, as opposed to the reasons which the government had been articulating since 1990. Either way, viewed through the lens of candour, this is a concerning communication. Furthermore, it may be thought to illustrate the Government’s determination to avoid any payment scheme for those with Hepatitis C, come what may.

Responding to Charles Dobson’s email, Paul Pudlo acknowledged that the Secretary of State had consistently opposed any form of no-fault compensation but interpreted his position as being that it was preferable to live with the anomaly of the HIV scheme than to remove it by making it the norm. This “*candid*” position was said to be difficult to defend publicly “*since it could be taken as a suggestion that the HIV infected patients are not deserving of the compensation they receive.*” Paul Pudlo referred to a tacit recognition that, with the benefit of hindsight, the distinction made between the plight of HIV and Hepatitis C infected people with haemophilia was “*looking increasingly tenuous. It is now known that HIV is not as rapidly fatal as was thought at the time of the settlement but HCV is worse than predicted.*”

731 Written Statement of Stephen Dorrell para 2.64 WITN5290001

732 Note of Compensation for Haemophiliacs with Hepatitis C meeting 24 April 1996 DHSC0042289\_144

733 Memo from Ann Towner to Anne Murie 19 April 1996 p3 WITN5290031

734 Email from Charles Dobson to Ann Towner 23 April 1996 DHSC0004756\_042

*This erosion of the clinical difference between the groups has weakened the proposition that HIV was a special case.* Paul Pudlo was not in favour of running the argument suggested by Charles Dobson, querying whether it was consistent with *“the HIV legal view at the time”*. He was also unconvinced that the Department of Health could argue that the legal position vis a vis Hepatitis C was *“so much better”*.<sup>735</sup>

Commenting on this in his written statement to the Inquiry, Stephen Dorrell confirmed that his evidence to the Health Committee set out his view clearly: *“I did not (and do not) support the principle of no-fault compensation payments to NHS patients who suffer as a result of the inevitable risks associated with medical treatment.”*<sup>736</sup> The implicit characterisation of the transmission of deadly viruses – HIV and Hepatitis C – as *“inevitable risks associated with medical treatment”* is surprising. It is also wrong.

At his April 1996 meeting with the Secretary of State, it had been suggested that John Marshall’s best course of action might be to seek funds which had not been allocated for health purposes. This led to John Marshall appealing directly to the Prime Minister again. He asked whether help could come from the contingency fund rather than the Department of Health’s existing budget.<sup>737</sup> The Prime Minister’s response suggested that the Government had given the question of compensation *“very careful consideration, including the Irish scheme.”* *“Great sympathy”* was expressed but the Prime Minister said that it was *“better to spend money provided for health care, from whatever source, on treating patients than on payments to people who received the best possible treatment available at the time.”*<sup>738</sup>

On 25 June 1996 John Horam met John Marshall and stressed that it would be very difficult to justify *“payments of this magnitude with so many competing demands on the health service.”* He also indicated that it was extremely unlikely that the Treasury would agree to the cost being met through the Government’s contingency reserves.<sup>739</sup>

On 29 July 1996 judgment was delivered by the High Court in a case involving the transmission of CJD by human growth hormone. John Horam’s private office asked officials if there was

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735 Memo from Paul Pudlo to Charles Dobson 23 April 1996 p2 DHSC0004756\_041

736 Written Statement of Stephen Dorrell para 2.69 WITN5290001. Later in his statement he states that it is open to governments, as a separate issue, to provide support to groups of citizens who have particular difficulties, but that he considers it important that consideration of these humanitarian factors *“is not confused with payments to people who receive care to a standard which is later enhanced by developing scientific understanding.”* Written Statement of Stephen Dorrell para 2.122 WITN5290001. If this is intended as a characterisation of the position of those infected with HIV and Hepatitis C through blood and blood products, it is a mischaracterisation. His use of the word *“inevitable”* is one which must have derived from what he had been given to understand – that the infections were unavoidable, and the treatment had been the best available in the light of knowledge at the time: thus on the facts as he then understood them to be, they would fall within a class which he thought then, and would think now, did not justify *“no fault compensation”*.

737 Letter from John Marshall to John Major 29 April 1996 p1 DHSC0006324\_163

738 Letter from John Major to John Marshall 16 May 1996 HSOC0014325. The Prime Minister’s letter referred to the possibility of lottery grants from the National Lottery Charities Board. Although there has been some criticism of this suggestion, because recourse to the charity sector was plainly not an answer and not a discharge of the Government’s moral responsibilities, it is right to note that this was an issue that had been raised in John Marshall’s letter to the Prime Minister to which the latter was merely responding.

739 Note of John Marshall and Sir Geoffrey Johnson-Smith meeting 25 June 1996 p1 DHSC0041255\_072

anything in the judgment that might affect the terms of the still outstanding reply to the Haemophilia Society regarding those infected with Hepatitis C. Kevin Guinness suggested that the cases were “*very different in one way, in that, with hepatitis, it was known by all (including the patients) that infection was being transmitted, though it was not necessarily thought to have long-term consequences*”.<sup>740</sup> This was repeated in advice provided to the Minister in September 1996, which asserted that the judge found the Department of Health negligent “*primarily on the grounds that neither treating physicians nor recipients of human growth hormone (HGH) treatment were made aware of the risk of contamination at the earliest opportunity and that action to reappraise the HGH programme was not taken as urgently as it should have been once that risk was known.*” Hepatitis C was very different because “*the risk of infection via blood products was known to all concerned – including the patients. The problem was that there was no reliable test available to screen the blood. The Department is satisfied that action to introduce screening of blood for Hep C was taken as quickly as possible once a reliable test had been identified.*”<sup>741</sup> Lord Horam, in his evidence to the Inquiry, acknowledged that it did not occur to him to question how a civil servant could state with such confidence that all patients knew that infection was being transmitted, adding “*it puzzles me that he could know that.*”<sup>742</sup> The evidence which this Inquiry has received establishes that, contrary to officials’ assertions, the risk of infection via blood products was not known to all patients.<sup>743</sup>

The decision not to make any form of payments for those infected with Hepatitis C was communicated to the Haemophilia Society in October 1996. The terms of the refusal repeated that there had been no negligence on the part of the NHS and that “*Tragic though it is that the very treatment designed to help those patients infected should have caused them harm, there can be no question that they received the best treatment available at the time. That treatment was essential for their survival.*” Other reasons included the belief that this would “*very quickly*” develop into a general no-fault compensation scheme and that it would involve the expenditure of substantial sums of public money that was best used in direct patient care.<sup>744</sup> In his response, as well as expressing deep disappointment, Reverend Tanner reiterated that the Haemophilia Society’s request had been for a “*compassionate approach to the strong moral arguments involved*”, which would not set a precedent for no-

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740 Memo from Kevin Guinness to Marguerite Weatherseed 29 July 1996 DHSC0006348\_055

741 Paper on current issues WITN5294013 provided under cover of a minute from Christine Corrigan, Memo from Christine Corrigan to Marguerite Weatherseed 11 September 1996 DHSC0041255\_064

742 Lord John Horam Transcript 29 June 2022 pp101-102 INQY1000217

743 Moreover, those who had been told that they may have or have had non-A non-B Hepatitis were frequently told that the infection was largely benign and had little by way of long-term consequences, when the truth was that doctors did not know exactly what the long-term consequences might be, but had good reason to suspect that they might be serious. Advice about a risk where much is unknown should explain that this is the case. This almost certainly rarely if ever happened so far as non-A non-B Hepatitis was concerned.

744 Letter from John Horam to Reverend Tanner 1 October 1996 pp1-2 HSOC0023572. A similar response was given to the Manor House Group. Letter from John Horam to Reverend Tanner 25 October 1996 HSOC0003918



fault compensation. He pointed out that many had lost their jobs and more than 60 people with haemophilia had already died because of Hepatitis C infection.<sup>745</sup>

On 7 October 1996 the *World In Action* documentary *Tainted Blood* was broadcast. It included John Horam stating “Remember they are alive first of all, I mean they’ve had the gift of life from the blood products they received, and in addition some of them have indeed got hepatitis C. But first of all they are alive and secondly the onset of hepatitis C, while very severe, in the case of probably one in five, undoubtedly, indeed leading to cirrhosis of the liver and death, er in many others is not so severe. So lets [sic] look at it in perspective.” It also recorded Professor Howard Thomas explaining that “the patient with hepatitis C is equally deserving [as the patient with HIV] just because it takes a longer time for him to develop symptomatic disease doesn’t mean it’s any less serious.”<sup>746</sup>

Alf Morris took up the issue with the Prime Minister, referring to the “anguish and disbelief” at the Government’s position and seeking a meeting.<sup>747</sup> The Prime Minister was advised to, and did, decline, emphasising that the Government saw “a clear distinction between the plight of those who contracted HIV as a result of NHS treatment and those infected with hepatitis C.”<sup>748</sup>

In a powerful speech in Parliament on 11 December 1996 John Marshall raised the question of compensation again: “it seems to me fundamentally wrong that individuals who suffer as a result of treatment given on the national health service should be ignored by society.” He emphasised that many would die from Hepatitis C, and that for many others “the quality of life will deteriorate dramatically, and they will suffer severe physical and economic hardship”.<sup>749</sup> He was indeed right, as the evidence which this Inquiry has heard attests. John Horam, in response, maintained the government line.<sup>750</sup>

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745 Letter from Reverend Tanner to John Horam 3 October 1996 HSOC0014299

746 World in Action Tainted Blood Transcript 7 October 1996 p10, p24 HSOC0008602

747 Letter from Alf Morris to John Major 7 October 1996 HSOC0004852

748 Letter from Shaun Gallagher to Mark Adams 23 October 1996 DHSC0041256\_124. The background note accompanying the letter suggested that it might take 20 to 30 years to develop cirrhosis and that the majority of those years would be “trouble free in terms of ill health and only a small percentage will actually die of liver disease.” Background note on Haemophilia Society Campaign p2 DHSC0041256\_126. Letter from John Major to Alf Morris 29 October 1996 HSOC0026600

749 Hansard parliamentary debate on Haemophiliacs (Compensation) 11 December 1996 p1 DHSC0041255\_130. On the same date Reverend Tanner sent a petition to the Prime Minister, referring to the “great depth of feeling among the haemophilia community that they are being dealt with unjustly by the Government and are simply being forgotten and some left to die.” Accepting that there were some differences between HIV and Hepatitis C, he emphasised nonetheless that there were strong similarities and that “people with haemophilia infected with hepatitis C are suffering hardship and illness now; many have lost their jobs because of their HCV infection and are trying to make ends meet on benefits. We need action now.” The Government’s stance was described as both illogical and morally indefensible. Letter from Reverend Tanner to John Major 11 December 1996 pp1-2 HSOC0000161. John Horam responded on 19 December 1996. Letter from John Horam to Reverend Tanner 19 December 1996 pp3-4 HSOC0000161

750 In relation to treatment with Factor 8 concentrates, he said “It was undoubtedly the best treatment available for people with haemophilia in the light of medical knowledge at the time. However, medical procedures rarely come without risk, and those are not always known about or capable of being guarded against in time.” He emphasised again that this was treatment “essential for their survival. There was no alternative”. Hansard parliamentary debate on Haemophiliacs (Compensation) 11 December 1996 pp3-4 DHSC0041255\_130

In February 1997 Alf Morris again raised the question of compensation, urging the Secretary of State to “act now”. He said that “*In none of the campaigns I have been closely involved in here over the years – among them those for the thalidomide victims, for children with dyslexia and autism, for war widows and for haemophiliacs infected with HIV – have I had so strong a sense that no campaigning should be necessary to right such an obvious wrong.*”<sup>751</sup>

## The appeal to the new Government

On 1 May 1997 a general election was held, a new government, under Tony Blair, came in, and a new Secretary of State for Health, Frank Dobson, was appointed. The Haemophilia Society renewed its efforts to persuade the Government to establish a financial assistance scheme for those infected with Hepatitis C. It wrote to the Secretary of State on 12 May 1997, asking the new Government to act quickly to review the previous Government’s policy.<sup>752</sup> It also wrote to Baroness Margaret Jay, who had been appointed as Minister of State for Health, on 23 May 1997, reminding her that she had previously spoken in support of financial recompense for those infected with Hepatitis C in the House of Lords.<sup>753</sup> On 16 June 1997 a minute to the Secretary of State’s office strongly recommended that the Secretary of State agree to review the issue.<sup>754</sup>

An issue that was also being considered within the Department of Health at this time was the question of compensation for those infected with CJD from human growth hormone, which was the subject of litigation. A minute dated 28 May 1997 regarding the setting up of a meeting to discuss that issue bears this handwritten note to the Permanent Secretary: “*I think MH(PH) would like to give more compensation to haemophiliacs but officials are trying to steer her away.*”<sup>755</sup> MH(PH) was the Minister of State for Public Health, Tessa Jowell.

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751 Hansard parliamentary debate on NHS 24 February 1997 p3 HSOC0003170

752 Letter from Reverend Tanner to Frank Dobson 12 May 1997 WITN3430267

753 Letter from Reverend Tanner to Baroness Jay 23 May 1997 HSOC0004095. On 30 January 1995 Baroness Jay had asked the then Parliamentary Under-Secretary of State of Health Baroness Cumberlege “*is she aware that there was considerable and justifiable anger at the length of time it took the Department of Health to come to an opinion and a decision about the Macfarlane Trust on HIV and AIDS compensation? Will she seek to avoid a similar atmosphere developing and a similar sense of unjust treatment of people with haemophilia who have been infected by Hepatitis C? There really is no difference in the position which the Minister has explained between those infected who have Hepatitis C and those who have HIV and AIDS.*” Hansard parliamentary debate on Haemophiliacs: Contaminated Blood Transfusion 30 January 1995 p2 NHBT0009775. On 15 March 1995 she had expressed the view that the “*moral case is made completely and clearly for immediate hardship payments to those who are already ill and to those who are the dependants of those who have already died. I would then like to see an extension of the McFarlane [sic] Trust to provide some kind of financial adjustment ... financial funding for those who have the Hepatitis C virus.*” Hansard parliamentary debate on The McFarlane [sic] Trust 15 March 1995 p6 BART0000791

754 One reason for the recommendation for review was that the former Shadow Health Minister had given a clear undertaking to do so. Memo from Christine Corrigan to Anne Murie 16 June 1997 p1 DHSC0006572\_062

755 Email from Maria Farrugia to Neil Townley and others 29 May 1997 WITN7410011. The meeting that was subsequently held on 10 June 1997 records the Minister of State confirming that the Department “*needed to hold the line.*” Minutes of HGH/CJD Litigation meeting 10 June 1997 p1 WITN7410012

On 10 September 1997 the Haemophilia Society met the Secretary of State to press their case.<sup>756</sup> The advice from officials to the Secretary of State in advance of the meeting referred to a recent decision not to provide compensation to patients infected with CJD through human growth hormone treatment and suggested that:

*“In the light of the decision relating to CJD, it would seem unlikely that SofS [Secretary of State] would wish to take a contrary line in relation to haemophiliacs and hepatitis C. The meeting is, however, principally an opportunity for SofS to listen to the Society’s views, which he can then consider further. We would recommend that SofS indicates to the Haemophilia Society at the meeting that he will not be making a decision immediately, but will need a short while to consider the matter further. If, having heard the Society’s representations, SofS wishes to reconsider the compensation issue afresh, officials will shortly provide fuller advice.”*<sup>757</sup>

The Secretary of State was also advised that if help were given to people with haemophilia, it would be difficult to justify not extending it to other people infected with Hepatitis C through blood and blood products, as had been the case for those infected with HIV through transfusion.<sup>758</sup>

Frank Dobson agreed to consider the Haemophilia Society’s points most carefully and said that he would write shortly.<sup>759</sup> Following the meeting his private secretary requested a note on *“the broader considerations surrounding both the compensation and Factor VIII issues including a draft reply for SoS to send to the Haemophilia Society.”*<sup>760</sup>

A meeting took place between the Haemophilia Society and Baroness Margaret Jay at the Labour Party conference at the end of September 1997, following which the Haemophilia Society sent her a note from Professor Eric Preston referring to *“clear and unequivocal evidence that there is an emerging risk of mortality from liver disease and liver cancer in the UK haemophilia population in both HIV-infected and HIV-uninfected.”*<sup>761</sup>

There was a delay in officials providing the Secretary of State with the information which he had requested due to issues relating to the emergence of variant Creutzfeldt-Jakob Disease

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756 The Haemophilia Society’s briefing for the meeting recorded that people with haemophilia infected with Hepatitis C were infected *“at exactly the same time and by the same route as those infected with HIV ... We believe that the moral responsibility accepted by the Government for those infected with HIV applies equally to those infected with HCV.”* Haemophilia and Hepatitis C – The case for financial recompense 19 August 1997 p2 HSOC0014405

757 Memo from Christine Corrigan to Anne Murie 8 September 1997 p3 DHSC0003883\_048

758 Background note on Compensation for haemophiliacs infected with Hepatitis C 8 September 1997 p2 DHSC0003883\_050

759 Note of Haemophilia Society, Manor House Group and Department of Health meeting 10 September 1997 p1 DHSC0046925\_074. In fact, it would not be until July 1998 that his decision was conveyed to the Haemophilia Society as the text goes on to explain.

760 Memo from Heather Rogers to Christine Corrigan and Dr Mike McGovern 10 September 1997 DHSC0038508\_090

761 Note on Liver Disease and Haemophilia 2 October 1997 p3 WITN7410017. The note referred to an analysis showing that mortality was 16.7 times higher than the general population for liver disease and 5.6 times higher for liver cancer.

(“vCJD”).<sup>762</sup> He had also been considering the introduction of recombinant Factor 8 and by February 1998 had decided that he would like to be able to announce its introduction. The belief of officials appears to have been that he would “*also be saying ‘no to Hep C compensation’ at the same time*”,<sup>763</sup> and a submission to the Secretary of State on 16 February 1998 recorded that it had been “*assumed on the hepatitis C ‘compensation’ issue, given the considerable implications to the wider NHS of agreeing to any such scheme, that you would wish to continue with the policy line which the Government has so far taken in response to representations from other groups ie to refuse such requests*”.<sup>764</sup> On 24 February 1998 a further submission provided a draft response to the Haemophilia Society which “*tried hard to be as sympathetic as possible in refusing compensation, without repeating too many of the standard arguments which have been put to them on many occasions in the past*.”<sup>765</sup> Contrary, however, to the assumption of officials, the Secretary of State had not yet reached a decision: a handwritten note from him asked for “*a short letter on ‘recombinant’ etc & say I’m still looking at the other issues*.”<sup>766</sup>

On 4 March 1998 the Secretary of State decided to write to the Prime Minister on the question of whether some form of compensation should be offered to people with haemophilia infected with Hepatitis C. This alarmed officials. With echoes of the departmental response to former ministers Gerald Malone and John Horam, they sent a minute the next day to Dr Graham Winyard, the DCMO, “*expressing concern that while SoS accepts that the Government could not afford a large compensation package, he feels that a small hardship fund like the MacFarlane Trust would be possible. Officials are concerned that significant funds would need to be diverted from patient care to fund it and that Treasury remain fundamentally opposed*.”<sup>767</sup>

Alarm continued to be expressed: on 6 April 1998 a minute recorded that “*We are in a rather difficult position in respect of those infected with hepatitis C through NHS treatment, because SofS seems inclined at present, contrary to the public Government line so far ... to consider making some form of special payments to haemophiliacs in this group*.”<sup>768</sup>

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762 Email from Sarah Casemore to Christine Corrigan 29 October 1997 WITN7410018, Email from Christine Corrigan to Mary Sandillon 29 October 1997 p1 WITN7410019, Memo from Dr Mike McGovern to Heather Rogers 26 November 1997 DHSC0045038\_038. The Secretary of State wrote to the Haemophilia Society on 28 November 1997 apologising for the delay and expressing the hope that he would reply before Christmas. Letter from Frank Dobson to Tony Wilson 28 November 1997 HSOC0016902

763 Memo from Christine Corrigan to Janet Grauberg 12 February 1998 WITN7410020

764 Memo from Christine Corrigan to the Secretary of State 16 February 1998 DHSC0006917\_078

765 Memo from Christine Corrigan to Fiona Anderson 24 February 1998 WITN7410021. The suggested reasons in the draft letter (which was not sent) included that “*where the ill effects [of treatment] could not have been predicted, or prevented, at the time, then they have to be balanced against the benefits of the treatment*.” Draft Letter to Chris Hodgson February 1998 p1 DHSC0046925\_053

766 Memo from Christine Corrigan to Fiona Anderson 24 February 1998 WITN7410021. The letter which the Secretary of State did send on 26 February 1998 addressed recombinant Factor 8 only, saying on the special payment scheme question that he could not yet give an answer. Letter from Frank Dobson to Chris Hodgson 26 February 1998 RHAL0000441\_002

767 Compensation for Haemophiliacs & Hepatitis C: Chronology DHSC0042461\_030. This is taken from a chronology produced a few years later by Charles Lister: the note of 4 March 1998 and the minute of 5 March 1998 have not been located.

768 Memo from Christine Corrigan to Grant Whiting 6 April 1998 WITN7410023

On 8 May 1998, in response to Frank Dobson’s request two months previously for a letter to send to the Prime Minister, civil servant Christine Corrigan wrote that there were a number of issues that needed to be determined before the letter could be prepared. A series of questions were set out and a meeting was suggested.<sup>769</sup> Dr Winyard wrote to the Permanent Secretary (Chris Kelly) on 12 May expressing his concern:

*“Secretary of State’s wish to pursue the possibility of compensation for Haemophiliacs damaged by Hepatitis C raises some major policy questions both about no fault compensation and the potentially even more elastic concept of ‘a moral liability’ of Government to compensate individuals and groups who have been damaged however inadvertently<sup>770</sup> by its actions ... It seemed to us that there are very real dangers in moving from specifics to general policy issues as is happening at present, even more so because apparently the Haemophilia Society are aware of Secretary of State’s intention to ‘write to No 10’.”<sup>771</sup>*

On 18 May 1998 Baroness Jay met officials to discuss the issue. She asked for a note to send to the Secretary of State: her own “clear position” was that “we must hold the line that the HIV decision was the ‘aberrant’ one and that we must resist this pressure for compensation.”<sup>772</sup> A note was duly produced and sent by the Minister of State to Frank Dobson on 1 June 1998. The note sought to persuade the Secretary of State against a scheme for people with haemophilia infected with Hepatitis C, which was not “feasible” for a number of reasons. These reasons included that there would be immediate pressure to extend the scheme to transfusion recipients (as to which “it would be very hard on equity grounds to resist”), the costs would be considerable (“We can imagine the likely response from Treasury!”) and (“most significant”) the wider implications of similar claims from other patient groups relating to harm from NHS treatment where negligence had not been proven in the courts. Baroness Jay’s advice was to “hold the line and resist the pressure for such payments” and that it was very important:

*“if patients are to have realistic expectations of the NHS, that they are encouraged to accept that virtually any treatment involves risk, and that while known risks will be drawn to their attention, and the NHS will always do its best for them, success cannot always be guaranteed. There may be an adverse outcome of*

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769 Memo from Christine Corrigan to Secretary of State 8 May 1998 DHSC0014990\_136

770 Dr Winyard has told the Inquiry that he was using “inadvertent” in the sense of “unintentional” and that whatever knowledge and understanding he had then of the circumstances in which people were infected would have come from internal Department of Health papers on the subject. Written Statement of Dr Graham Winyard para 29.4 WITN7606001

771 Memo from Dr Winyard to Chris Kelly 12 May 1998 DHSC0041163\_008. In his statement to the Inquiry Dr Winyard explained that he was “particularly concerned at the many potential problems that could arise from a drift into no-fault compensation (which I have always thought has many advantages) without detailed planning and costing, including securing agreement across Government.” Written Statement of Dr Graham Winyard para 29.1 WITN7606001

772 Memo from Fiona Anderson to Christine Corrigan 18 May 1998 p1 DHSC0004457\_040. In her written statement to the Inquiry Baroness Jay explained that she had no independent recollection of this meeting, but was sure that she was most strongly influenced by the arguments about creating a no fault compensation scheme and by the formidable logistical and medical problems referred to by officials. Written Statement of Baroness Margaret Jay para 11.8 WITN7410001

*any treatment, either in the short or longer term. The inescapable fact in this case is that, while it is undoubtedly very unfortunate that these patients contracted hepatitis C through their NHS treatment, without that treatment many – if not most – of them would not be alive today.”<sup>773</sup>*

A handwritten note on a copy of the submission of 8 May records:

*“I know Drs Metters & Winyard are really concerned about setting a precedent for no-fault compensation in the NHS. We did avoid it with HIV payments, but there’s a risk that – if we move on this – we’ll have to pay out on HTLV, nvCJD etc. The problem is explaining to the haemophiliacs with HIV & Hep C why we paid for one & not another. The answer proposed here is HIV was then thought to mean very short life span & very rapidly declining health. My feeling is that was illogical, but we could make things worse by allowing another special case. Maybe we resist this & pursue making the blood supply as safe as possible”<sup>.774</sup>*

A meeting to discuss the issue subsequently took place between Frank Dobson and Baroness Jay on 13 July 1998. A later document describes that “*MS(L) said that she felt personal discomfort with having to resist the plea but nevertheless felt it should be resisted.*”<sup>775</sup> It appears to be at this meeting that Frank Dobson agreed to maintain the existing policy: a minute from the Secretary of State’s Private Office recorded that the Secretary of State and Minister of State recognised that there would be criticism of the “*choice not to follow the HIV/AIDS scheme but are prepared to defend the position on the grounds that the HIV decision was taken on the basis of the understanding of the disease progression at that time.*”<sup>776</sup>

That decision was communicated to the Haemophilia Society on 28 July 1998. The Secretary of State explained that the Government had decided not to set up any form of payment scheme for the “*inadvertent harm*” of people with haemophilia infected with Hepatitis C.<sup>777</sup> The decision was announced in Parliament on the same day.<sup>778</sup> Thus Frank Dobson joined the small group of ministers (Gerald Malone, John Horam) who had seemingly wanted to make **some** provision for **some** Hepatitis C sufferers at least but who encountered resistance within the Department and ultimately continued the existing departmental line.

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773 Memo from Baroness Jay to Frank Dobson 1 June 1998 DHSC0006335\_028

774 Memo from Christine Corrigan to Frank Dobson 8 May 1998 DHSC0042287\_111. Emphasis in original. The notes are headed “*SofS: decision 1 for meeting 18/5*” and have what looks like the initial “*F*” at the end. It is not clear who made these notes but it may have been Fiona Anderson, the Secretary of State’s private secretary, who attended a meeting on 18 May with Baroness Jay, Dr Metters, Dr Winyard and Christine Corrigan. Memo from Fiona Anderson to Christine Corrigan 18 May 1998 DHSC0004457\_040

775 Compensation for Haemophiliacs & Hepatitis C: Chronology p2 DHSC0042461\_030. In her written statement to the Inquiry Baroness Jay could not recall how readily or not Frank Dobson came to share her view. Written Statement of Baroness Margaret Jay para 11.19 WITN7410001

776 Memo from Fiona Anderson to Christine Corrigan 14 July 1998 DHSC0041163\_003

777 Letter from Frank Dobson to Chris Hodgson 28 July 1998 p1 DHSC0016534

778 Hansard written answers on Hepatitis C 28 July 1998 DHSC0006894\_097

## Government attempts to hold the line

The Haemophilia Society did not let matters rest there. Advice to Baroness Helene Hayman (who had become Parliamentary Under-Secretary of State for Health in the Lords on the day of Frank Dobson’s announcement) in November 1998 explained that the campaign was being renewed and the Haemophilia Society was challenging each of the points in Frank Dobson’s letter through parliamentary questions and correspondence, as well as requesting a public inquiry.<sup>779</sup> There was no change of policy on the part of the Government, however.<sup>780</sup> Thus, for example, Baroness Hayman maintained the line in Parliament on 15 June 1999<sup>781</sup> and was advised to do so in correspondence.<sup>782</sup>

She appears to have had some doubts, however, about the claimed distinction between HIV and Hepatitis C.<sup>783</sup> Her statement explains that she “*clearly felt uneasy about the decision not to introduce a special payment scheme for haemophiliacs infected with Hepatitis C through NHS treatment.*”<sup>784</sup> By 1999 advances in treatment meant that it was more difficult to justify the difference in treatment of the two groups: “*I imagine I struggled with the existing policy that these two groups of people should be treated differently, given that they had received the same treatment with comparative levels of severe consequences.*”<sup>785</sup>

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779 Advice and draft reply to reach Private Office by 30 October 98 WITN4505003

780 See the statement of Baroness Hayman. Written Statement of Baroness Helene Hayman para 6.2 WITN5523001

781 Hansard written answer on Haemophiliacs Infected with Hepatitis C: Special Payments Refusal 15 June 1999 p1 WITN4505004A

782 Memo from Charles Lister to Baroness Hayman 9 July 1999 WITN4505005, Letter from Baroness Hayman to Lord Morris DHSC0041305\_138. This letter was not sent by Baroness Hayman: she wanted to have a meeting with officials to discuss the issue but she was then moved to a post as Minister of State in the Ministry of Agriculture, Fisheries and Food on 29 July 1999. Email from Lee McGill to Sheila Adam 22 July 1999 DHSC0041305\_121, Written Statement of Baroness Helene Hayman para 2.5 WITN5523001

783 A minute to her on 21 July 1999 recorded a discussion between Baroness Hayman and Dr Sheila Adam, who headed the directorate responsible for blood policy and wrote: “*you were clear that there is no easy solution here, and I can only agree with that. We have made a distinction between haemophilia and HIV and HCV, and this is difficult to explain logically.*” Memo from Sheila Adam to Baroness Hayman 21 July 1999 p1 DHSC0041305\_123. Civil servants involved in advising the minister cast doubt on the wisdom of having made any settlement for HIV in the first place. Charles Lister described it as “*arguably not very logical in the first place. It was very much a decision bound up with contemporary feelings about HIV although this was not reflected in the public statements made at the time ... However, from today’s perspective, there are enormous difficulties in making a distinction between haemophiliacs and others inadvertently harmed by NHS treatment.*” Email from Charles Lister to Sheila Adam 10 July 1999 DHSC0041305\_128. A higher executive officer working in his team observed that “*It is difficult that the 1987 statements attribute the HIV decision to the fact of another serious disease superimposed on the pre existing haemophilia. I have spoken informally to Roger Moore who [led the blood policy team] at the time. He said that the decision to introduce the scheme was an emotional one, made on the spur of the moment after a moving presentation to the then SoS by two young haemophiliacs. Before that moment there had been no intention whatsoever to agree to a scheme. RM described the decision as irrational.*” Email from Gwen Skinner to Mike McGovern and others 16 July 1999 WITN4505006

784 Written Statement of Baroness Helene Hayman para 6.4 WITN5523001

785 Baroness Hayman added that it was, on the other hand, an established principle that the NHS does not pay no-fault compensation and was aware that precedents could be set. Written Statement of Baroness Helene Hayman paras 6.10-6.11 WITN5523001

It is clear that the Government was finding it increasingly difficult to justify the distinction between HIV and Hepatitis C. Indeed it was this which led to Baroness Hayman's uneasiness. On 24 May 1999 Lord Alf Morris queried the suggestion that had been made on behalf of the Secretary of State that the social stigma of HIV and the danger of infecting partners were important considerations in granting special payments for HIV, and asked Baroness Hayman to point to where that was officially stated when the Major Government announced its HIV scheme.<sup>786</sup> Baroness Hayman sought advice on how to respond and in the internal correspondence it was suggested that the Secretary of State had been "*giving the view of the current Government, not attributing reasons to a past Government*".<sup>787</sup> That is not, however, consistent with the speaking notes prepared for Baroness Hayman which stated "*The special payment scheme for those infected with HIV ... was introduced in 1988. At that time there were very strong public attitudes to HIV – of stigma, and widespread fear of a new and untreatable fatal infection which was sexually transmitted*".<sup>788</sup> These notes clearly suggest that the reasons **at the time** the scheme was introduced related to stigma and transmission to partners. An internal email queried whether it was the case that "*we thought we were on weak legal ground in the HIV case ... When it comes down to what was or may have been said publicly I suspect that it is difficult to find any difference in the merits of the groups themselves ie between then and now.*"<sup>789</sup>

Following a further written answer which referred to the very high level of stigma,<sup>790</sup> the Haemophilia Society wrote to Baroness Hayman taking issue with what was being said, on the basis that it did not represent an accurate explanation of the Government's decision in 1987 to introduce a special payments scheme for those infected with HIV. Karin Pappenheim said that the Government's decision in 1987 "*was far more to do with the pressure of legal actions then being pursued, the large number of deaths from AIDS within the haemophilia community, the high profile of HIV in the media and all party pressure from within Parliament.*"<sup>791</sup>

Lord Philip Hunt took over from Baroness Hayman in July 1999 and in September attended a briefing with officials regarding the Hepatitis C issue. He was advised that ministers had taken a clear decision not to award a special payment scheme but that there was continued unhappiness and lobbying from the Haemophilia Society and some MPs and that the position was being reconsidered in Scotland by Susan Deacon Minister for Health and Community Care.<sup>792</sup>

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786 Hansard parliamentary question on Hepatitis C Infection 24 May 1999 p1 HSOC0023993

787 Memo from Gwen Skinner to David Dunleavy and Anita James 9 May 1999 DHSC0003214\_008

788 Information Pages on parliamentary responses to health issues p7 WITN5523012

789 Email from David Dunleavy and Gwen Skinner to Trish Fretten 11 June 1999 DHSC0041341\_244

790 Hansard written answer on Hepatitis C and Haemophiliacs 28 June 1999 DHSC0032341\_089. This answer was drafted so as to refer to the decision-making in 1998 by Frank Dobson and others, rather than the original decision-making in the late 1980s.

791 Letter from Karin Pappenheim to Lord Morris 23 June 1999 p1 HSOC0014604

792 Memo from Charles Lister to Lord Hunt 3 September 1999 DHSC0041304\_045, Campaign for Financial Assistance for Haemophiliacs Infected with Hepatitis C p1 SCGV0000169\_007



A line to take drafted for ministers in November 1999 sought to justify the difference between Hepatitis C and HIV on the basis that the decision to make special payments for the latter was an exception by the previous Government “*in circumstances where the only prospect for these patients was early death.*”<sup>793</sup>

In March 2000 Lord Hunt asked about the scope for doing more for people with haemophilia infected with Hepatitis C and requested an outline costing of a hardship fund. This advice was provided on 27 March and said that such a fund would be unlikely to be acceptable and that there would be a continuing demand for parity with the HIV scheme.<sup>794</sup>

In April 2000 Charles Lister, providing advice to Lord Hunt regarding the Hepatitis C litigation against the National Blood Authority, noted that settlement of that litigation (or an award of damages by the court) would give rise to “*inevitable claims of inequity from the Haemophilia Society, especially as the 400 or so haemophiliacs still alive with HIV also have HCV and signed an undertaking when they received their financial settlement not to take legal action on HIV or HCV.*”<sup>795</sup> Lord Hunt provided a note to Alan Milburn (who had succeeded Frank Dobson as Secretary of State) and Gisela Stuart (Parliamentary Under-Secretary of State in the House of Commons) in June 2000 regarding settlement of the Hepatitis C litigation, in which he noted that this had “*significant presentational difficulties given that we are refusing financial assistance to haemophiliacs infected with HCV through blood products prior to 1985.*” He wanted to ensure “*a clear and defensible distinction between settlement of this litigation and our continued refusal to compensate haemophiliacs infected with HCV through blood products on the basis of non negligent harm.*”<sup>796</sup>

In October 2000 Lord Hunt sought advice on what could be offered in terms of a package of care for those who had contracted Hepatitis C from blood products – with it being suggested that he was hoping to seek the permission of the Secretary of State “*to work up something more for HCV.*”<sup>797</sup> Officials provided him with a proposed pulling together of elements of a co-ordinated approach to problems associated with Hepatitis C treatment, observing that “*with the spotlight on Government compensation for people with variant CJD, and the NBA contesting HCV litigation in the Courts, it would be politic to announce an increased priority to the services for all those with HCV.*”<sup>798</sup> At this stage it was understood that the Scottish Executive was still seeking to maintain the common UK position against a payment scheme for those infected with Hepatitis C.<sup>799</sup>

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793 Email from Charles Lister to Department of Health colleagues p2 WITN4505008

794 Memo from Gwen Skinner to Lord Hunt 27 March 2000 p3 DHSC0004033\_003

795 Memo from Charles Lister to Lord Hunt 13 April 2000 p4 WITN5426246

796 The note was copied to Susan Deacon MSP and to ministers in Wales (Jane Hutt MS) and Northern Ireland (Bairbre de Brún MLA). Memo from Charles Lister to Lord Hunt 13 April 2000 p1, p3 DHSC5297720. The note also acknowledged that it was “*not true*” that the screening test for Hepatitis C was introduced as soon as the technology was available. This makes the line to take regarding screening, discussed in the *Lines to Take* section of this chapter, all the more indefensible.

797 Email from Sue Cartwright to Jane Verity and Charles Lister 24 October 2000 p3 DHSC0020784\_029

798 Memo from Jane Verity and Charles Lister to Sue Cartwright 26 October 2000 p1 DHSC0020784\_008, Memo from Lord Hunt to Alan Milburn DHSC0020784\_009

799 Written Statement of Charles Lister para 2.33 WITN4505002. A copy of the Scottish Executive’s report had been sent by Sandra Falconer of the Scottish Health Department to Charles Lister on 24 October

The reference to compensation for vCJD reflected the fact that, following publication of the report of the bovine spongiform encephalopathy (“BSE”) Inquiry on 26 October 2000, which recommended financial support for those with vCJD, the Government announced that it intended to put in place a compensation scheme for vCJD sufferers. Officials now sought to explain why the issue of compensation for people with haemophilia infected with Hepatitis C was different from vCJD.<sup>800</sup> The lines to take included the particularly distressing nature of vCJD (total absence of treatment, incurable and inevitably fatal), and sought to emphasise that the vCJD payments were not no-fault compensation but “*ex-gratia payments for a group of people who, because of exceptional circumstances, have endured and are enduring a particularly harrowing ordeal.*” This was distinguished from the position of those infected with Hepatitis C from blood products, on the ground that the products were heat treated as soon as the technology was available and there was thus no legal liability to justify compensation.<sup>801</sup> The plight of individuals and families affected by vCJD was described as “*the result of a unique set of circumstances for which society as a whole must bear a moral responsibility.*”<sup>802</sup> The Secretary of State wrote to Baroness Jay on 22 November 2000 explaining that he was “*convinced*” that both decisions (ie to make ex gratia payments to people with vCJD and the continued refusal to compensate people with haemophilia infected with Hepatitis C) “*are perfectly defensible on their own merits.*”<sup>803</sup>

In 2001 there was a further intensification of the campaign for financial assistance, with requests from Lord Morris and Edward O’Hara MP to meet the Prime Minister,<sup>804</sup> campaigners from the Manor House Group and Haemophilia Action UK staging a protest march demanding compensation;<sup>805</sup> an adjournment debate in the House of Lords; repeated parliamentary questions from Lord Morris; an Early Day Motion from Dr Brian Iddon MP; and the Haemophilia Society commencing its “Carpet of Lilies” campaign in May. Moreover on 26 March 2001 the judgment of Mr Justice Burton in *A and Others v National Blood Authority* was handed down.<sup>806</sup>

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2000; the letter stated that Susan Deacon MSP considered it an important general principle that the NHS should not pay compensation for non-negligent harm. Letter from Sandra Falconer to Charles Lister 24 October 2000 p1 WITN4505011

- 800 A briefing meeting to consider the BSE Inquiry report took place on 11 October 2000 attended by (amongst others) the Secretary of State and the Permanent Secretary (Chris Kelly). The note of the meeting records the Secretary of State asking whether providing compensation would impact on the current Hepatitis C litigation. The Permanent Secretary made two observations: the first was that this presented as a particularly horrendous case “*caused by feeding people infective material.*” The second was that people felt misled by a Government which did not make all the facts available. He commented that “*While this could be setting a precedent, it might be a precedent which ought to be set.*” Note of BSE Inquiry Report briefing meeting 11 October 2000 p2 DHSC0006245\_007. What does not appear to have been picked up is that both these points were equally applicable to the position of those infected with Hepatitis C: they had had “*infective material*” inserted directly into their bodies, and they absolutely felt misled by a Government that had not made all facts available.
- 801 Email from Charles Lister to Stephen Waring and others 31 October 2000 p2 WITN4505014
- 802 Memo from Jill Taylor to Lord Hunt 15 December 2000 p6 WITN4505016
- 803 Letter from Alan Milburn to Baroness Jay 22 November 2000 p1 CABO0000123\_013
- 804 Memo from Jill Taylor to Sue Cartwright and Robert Allan 3 January 2001 WITN4505017
- 805 Written Statement of Charles Lister para 2.40 WITN4505002. David Tonkin, of the Manor House Group, describes six members “*walk down Downing Street and present letters outlining their personal plights to Tony Blair.*” Written Statement of David Tonkin para 58 WITN1567008
- 806 *A and Others v National Blood Authority* Judgment 26 March 2001 PRSE0003333

In July 2001 the Parliamentary Under-Secretary of State for Public Health, Yvette Cooper, requested a position paper in light of the High Court judgment, setting out options. The submission provided to her noted that although the judgment only placed a legal obligation to make payments to those awarded damages, “*it introduces further questions of inequity and increases the moral pressure to do so.*”<sup>807</sup> The submission recognised that further instances of payment for non-negligent harm in the NHS “*will not necessarily erode the general rule*” although it would be important to “*re-emphasise the Government’s own parameters for such payments to contain any impact on the NHS.*”<sup>808</sup> The range of options identified included lump sum payments and/or a hardship fund for all or some people with haemophilia infected with Hepatitis C. The advice from officials was that if ministers wished to consider payments, the recommended option was a hardship fund solely for people with haemophilia whose Hepatitis C had caused severe liver disease.<sup>809</sup>

In early July Yvette Cooper approved an amended line to take in response to an Early Day Motion regarding the Carpet of Lilies campaign, indicating that ministers were “*reviewing the case for compensation*” in light of representations from parliamentarians, the Haemophilia Society and other lobby groups.<sup>810</sup>

In responding to questions raised by Yvette Cooper, Charles Lister advised that it would be difficult to provide payments to people with haemophilia without also making payments to those infected through blood transfusion. Reference was made to other groups seeking compensation; however Hepatitis C could be distinguished as exceptional as a “*devastating, debilitating disease*” which could lead to cirrhosis and liver cancer.<sup>811</sup>

In September 2001 a meeting was held with the Minister of State for Health, John Hutton, who did not think that offering compensation was an option but asked officials to look into providing a social care support package similar to that of the vCJD scheme.<sup>812</sup>

Shortly thereafter, at the beginning of October 2001, the Scottish Parliament’s Health and Community Care Committee published its report, calling on the Scottish Executive to provide financial support to all who were infected with Hepatitis C as a result of blood transfusion or blood products in Scotland.<sup>813</sup> The report further recommended that the level of financial assistance awarded should be determined on the basis of need. A briefing prepared for the meeting of the Joint Ministerial Committee on Health (involving ministers from across the

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807 Memo from Briony Enser to Yvette Cooper 2 July 2001 p1 DHSC0041379\_177

808 Memo from Briony Enser to Yvette Cooper 2 July 2001 p3 DHSC0041379\_177

809 Memo from Briony Enser to Yvette Cooper 2 July 2001 p4 DHSC0041379\_177, Information Pages on Hepatitis C options p5 DHSC0020756\_025

810 Email from Helene Shaw to Marsali Caig 5 July 2001 p2 WITN4505022, Written Statement of Charles Lister para 2.47 WITN4505002

811 Memo from Charles Lister to Yvette Cooper 19 July 2001 p2 DHSC0006983\_129, Written Statement of Charles Lister paras 2.49-2.52 WITN4505002

812 Email from Jane Colman to Charles Lister and Vicki King 12 September 2001 p2 DHSC0004363\_090. The advice subsequently provided recommended that the Minister await the outcome of a report from the Department of Health’s Hepatitis C Steering Group. Memo from Charles Lister to John Hutton 12 November 2001 pp4-5 DHSC0004601\_021

813 Health and Community Care Committee Report on Hepatitis C 2001 MACK0001929\_001

UK) on 22 October 2001 recognised that the existing line would be difficult to sustain in the rest of the UK if the Scottish Executive “*commits to the Scottish Parliament report.*”<sup>814</sup>

On 13 November John Hutton agreed to hold the policy line that no payments would be made in respect of Hepatitis C infection through blood and blood products except where awarded by the courts.<sup>815</sup> The next day, responding to an adjournment debate, and whilst acknowledging that the issue of compensation was “*the most difficult decision of all,*”<sup>816</sup> he reiterated the policy of successive governments (“*that compensation, or other financial help to patients, is paid only when the NHS or individuals working in it are at fault*”) and his belief that the NHS had not been at fault.<sup>817</sup> The same day he spoke to Susan Deacon, explaining that he was “*holding the line on compensation.*” He told her that there was “*anxiety*” that a new administration in Scotland might opt for a “*different and conscious change of position*”, which would “*create significant difficulties for us if people in Scotland can be compensated but those in England cannot.*” Susan Deacon indicated that she was not planning to do so (although she recognised that she could not predict the position “*further down track*”) and that the Scottish Executive wanted to look at the issue from a UK perspective (“*this is an issue which shouldn’t have a different approach north and south of the border.*”)<sup>818</sup>

By February 2002 the decision had been taken in Scotland to establish an expert group under the chairmanship of Lord Donald Ross to report on the question of compensation. In May 2002 Charles Lister advised Yvette Cooper that “*Until late last year, Scottish Ministers were taking the same line as us on the hepatitis C compensation issue. Under pressure from the Scottish Parliament, this can no longer be guaranteed.*” It was also noted that Michael Connarty MP<sup>819</sup> had made a request for papers relating to Frank Dobson’s consideration of the compensation issue, which had been made “*under the assumption that a detailed analysis would have been undertaken by the Department.*” Charles Lister advised that the papers showed this not to have been the case, and that the debate had been focused around concerns that such a scheme would open the floodgates to further claims. Further, if the papers were released, “*they will show that Frank Dobson was minded to support a scheme limited to haemophiliacs with hepatitis C but was persuaded from this by officials and Margaret Jay.*”<sup>820</sup>

Yvette Cooper met the Manor House Group on 15 May 2002, at which those in attendance explained that clinicians and the medical community had not given people with haemophilia all the information they had at the time so that patients could make a fully informed decision about which treatment to use. The minutes record the Minister agreeing to ask officials

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814 Joint Ministerial Committee on Health briefing on High Court Ruling and Hepatitis C Compensation p65 DHSC5302493

815 Email from Jane Colman to Charles Lister 13 November 2001 SCGV0000247\_039

816 Email from Jane Colman to Vicki King and others 15 November 2001 p19 DHSC0032036\_047

817 The Minister acknowledged during the debate that some people with Hepatitis C experienced social prejudice and discrimination. Email from Jane Colman to Vicki King and others 15 November 2001 p19, pp21-22 DHSC0032036\_047

818 Email from Linda Fenocchi to Bob Stock 14 November 2001 pp2-3 SCGV0000247\_036

819 Chair of the All-Party Group on Haemophilia.

820 Memo from Charles Lister to Yvette Cooper 8 May 2002 p3 DHSC0041379\_025

to refer to the papers from the period to get a fuller picture of what the known risks were, suggesting that clinicians might not have emphasised the seriousness of Hepatitis C as a risk factor because it was not fully appreciated until at least the late 1980s.<sup>821</sup> The existing government line regarding compensation was repeated. The following month Hazel Blears, who had succeeded Yvette Cooper, met the Haemophilia Society and Michael Connarty and advised that officials were looking at the compensation proposals recently submitted by the Haemophilia Society.<sup>822</sup>

Following the production of the preliminary report of the expert group chaired by Lord Ross in September 2002,<sup>823</sup> the Secretary of State for Health, Alan Milburn, remained unequivocal in his opposition to a Hepatitis C scheme, and agreed a line that “*The Department of Health in England has advised that it has no intention of initiating any scheme for compensating this group.*”<sup>824</sup>

On 4 November 2002 Malcolm Chisholm, the Minister for Health and Community Care in the Scottish Government, called Alan Milburn to inform him that the expert group under Lord Ross was about to publish a preliminary report calling for financial and other practical support for all people infected with Hepatitis C through blood, blood products and tissues, and that Scottish ministers felt that they “*had to offer something*”.<sup>825</sup> It was intended that an announcement would be made on 6 November. The Secretary of State suggested that this would be a “*grave mistake*”, “*a slippery slope to payments running into millions across the UK*” and that Malcolm Chisholm MSP should “*tough it out.*”<sup>826</sup>

The question was raised as to whether this was truly a devolved matter, and the Secretary of State was “*very clear that we need to find some way of showing that the Scots don’t have the devolved power to go it alone on this, and thereby prevent them going ahead with any kind of announcement on [6 November].*”<sup>827</sup> In response Charles Lister, after speaking to the Department for Work and Pensions, provided a submission on 5 November 2002 which recorded legal advice that the scheme could arguably be a social security rather than a health issue (and thus not within devolved powers). He advised that this should be raised with Scotland’s First Minister, Jack McConnell, and that the Secretary of State should

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821 Minutes of Yvette Cooper and Manor House Group meeting 15 May 2002 p2 WITN4505032

822 Minutes of Self-Sufficiency in Blood Products meeting 1 July 2002 p2 DHSC0003606\_083, Memo from Robert Finch to Hazel Blears 27 June 2002 pp2-3 DHSC0041305\_030. The Haemophilia Society’s proposals reflected the report of the Hepatitis C Working Party which it had established and which reported in June 2002. Report of the Hepatitis C Working Party June 2002 HSOC0005927

823 Preliminary Report of the Expert Group on Financial and Other Support September 2002 HSOC0003349

824 Email from Charles Lister to Mary Agnew and others 6 September 2002 p1 WITN4505033, Written Statement of Charles Lister para 2.76 WITN4505002. It is noted that in his evidence to the Inquiry, Alan Milburn suggested that the CMO was “*leading work on rising NHS litigation costs and the response to*” the clinical negligence system at the time, and that the CMO considered and rejected the case for a ‘no-fault’ compensation scheme for Hepatitis C in his 2003 report *Making Amends, A Consultation Paper*. Written Statement of Alan Milburn para 8.6 WITN6942001

825 Written Statement of Alan Milburn para 12.1 WITN6942001

826 Email from Sammy Sinclair to Charles Lister 4 November 2022 DHSC0042275\_129

827 Email from Sammy Sinclair to Charles Lister 4 November 2022 DHSC0042275\_129

request that Scotland not give any public indication that they were exploring a financial package until this issue had been resolved.<sup>828</sup>

In the Scottish Executive's news release welcoming the report on 6 November 2002, Malcolm Chisholm did not commit to the recommendations but indicated that there were complex medical, legal and financial considerations to take into account and that the Executive was looking at "*the interface with the social security system*".<sup>829</sup>

On 29 January 2003 the Scottish Executive Cabinet agreed that £25,000 be paid to those currently alive with Hepatitis C and a further £25,000 to those who developed cirrhosis. A review of costings by Scottish officials led to a decision that the figures would be £20,000 and £25,000 and this was reported to the Health and Community Care Committee in a statement from Malcolm Chisholm. It was subject to resolution of the issue regarding devolved powers, in relation to which the advice of Law Officers was sought.<sup>830</sup> Charles Lister emailed Hazel Blears's Private Office alerting her to this announcement and setting out the current media line that the Government's position remained that "*a special financial assistance package for this group is not justified*".<sup>831</sup>

In April 2003 advice was provided to Hazel Blears by the blood policy team regarding a response to the Haemophilia Society's proposals. It was recommended that the position remain that compensation was not payable. Law Officers' advice was still awaited on the devolution issue. The conclusion of the submission noted:

*"the position remains that there is no further funding available over the next three years. There is also a major concern that any compensation payment made to haemophiliacs with hepatitis C could open the floodgates for other groups who are currently seeking compensation ... SofS has consistently held that compensation is not payable to haemophiliacs infected with hepatitis C and that an exception cannot be made to the general rule that compensation or financial help is only given when the NHS or individuals working in it have been at fault."*<sup>832</sup>

Handover notes prepared in May 2003 by Charles Lister for his successor recorded the current position that:

*"Ministers here are sticking strongly to the no compensation line but Scottish Ministers have weakened ... SofS asked us to see if a way could be found to*

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828 Memo from Charles Lister to Sammy Sinclair and others 5 November 2002 p3 WITN4505036. On 5 November 2002 Charles Lister wrote that he had spoken to a Department for Work and Pensions official "*who has come up with an argument we can give SofS to deploy*." Email from Charles Lister to Kate Darwin and others 5 November 2002 p1 DHSC0020878\_013

829 Scottish Executive Press Release *Chisholm Welcomes Expert Group Preliminary Recommendations* 6 November 2002 p1 SCGV0000192\_005

830 Submission from Bob Stock to the Minister of Health and Community Care 29 January 2003 p2 SCGV0000251\_018. It appears that the request for advice from law officers was not made until 30 January 2003: Letter from Alan Williams to the Legal Secretary to the Advocate General for Scotland 30 January 2003 WITN6942021

831 Email from Charles Lister to Hazel Blears' Private Office 29 January 2003 p2 DHSC0046315\_070

832 Memo from Jill Taylor to Hazel Blears 9 April 2003 p3 DHSC5320619

*stop this. The result was a legal challenge saying that any payment scheme to haemophiliacs would be a social security scheme and therefore outside Scotland's devolved powers. This issue is currently with the law officers for a determination and we are expecting them to give a view very soon."*<sup>833</sup>

## The decision, finally, to make ex gratia payments to those infected with Hepatitis C

On 13 June 2003 John Reid replaced Alan Milburn as Secretary of State for Health and on 17 June 2003 Richard Gutowski, who had taken over from Charles Lister, provided a background note and a line to take for the Secretary of State in anticipation of approaches from Malcolm Chisholm and Jack McConnell. The note described some recipients of blood products having been "*inadvertently infected*" prior to the viral inactivation of blood products in 1984 and the introduction of donor screening in 1991. Officials saw no justification to move away from the existing line to take.<sup>834</sup> A few days later the Law Officers' opinion was received confirming that this was a devolved matter.<sup>835</sup> The effect of this was that the UK Government had no power to stop Scotland proceeding with its proposed scheme.

By 23 June the new Secretary of State had formed the view that "*given both the precedent on HIV and the likely Scottish decision to now go ahead, it looks as though we will on the basis of fairness have to go down the compensation (ex-gratia) route.*"<sup>836</sup> A meeting with the Chief Secretary to the Treasury and the Secretaries of State for Scotland and for Work and Pensions took place on 25 June, at which it was agreed that "*Wales and Northern Ireland will also need to be brought on board*". The Chief Secretary to the Treasury was "*very non-committal*" on the financing of an English scheme.<sup>837</sup>

Further discussions took place between officials and ministers over the following weeks about how a scheme could be structured and what payments should be made.<sup>838</sup> As at

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833 Blood Policy handover notes May 2003 p6 DHSC0041246\_045

834 Memo from Richard Gutowski to Sammy Sinclair 17 June 2003 p1, p3 WITN5292021. Richard Gutowski told the Inquiry that in order to write that there was no justification to move away from the existing line he would have had discussions with senior officers in the Health Protection Division. Richard Gutowski Transcript 10 June 2022 p27 INQY1000214

835 Emails between Graham Bickler, Richard Gutowski, Sammy Sinclair and Richard Douglas 20-24 June 2003 DHSC5320726

836 Emails between Graham Bickler, Richard Gutowski, Sammy Sinclair and Richard Douglas 20-24 June 2003 p2 DHSC5320726

837 Email from Sammy Sinclair to Richard Gutowski 25 June 2003 p1 WITN5292023

838 See for example a submission to John Reid, the Secretary of State for Scotland, Chief Secretary, and Secretary of State for Work and Pensions in which it was recorded that the Treasury had said no additional funding would be available, and a record of a meeting of officials from the Department of Health and Scottish Executive. Submission on Compensation Scheme for Hepatitis C 1 July 2003 p5 WITN5292023A, Minutes of Scottish Executive and Department of Health meeting 30 July 2003 DHSC0004421\_141. The Treasury's position was set out in writing on 27 August 2003. Letter from Paul Boateng to John Reid 27 August 2003 DHSC0014997\_116

31 July 2003 a UK wide scheme was favoured, but Wales and Northern Ireland had not yet been informed of developments.<sup>839</sup>

On 29 August 2003 John Reid announced that England would have an ex gratia payment scheme, a decision made “*on compassionate grounds*”.<sup>840</sup> Similar announcements were made in Scotland, Wales and Northern Ireland. As described in the following chapter, it took until July 2004 for the Skipton Fund, as it was to be called, to be set up.

Thus ten days after taking up his position as Secretary of State, John Reid reversed the line that had been adhered to for over ten years, and opted for a form of financial support for Hepatitis C sufferers infected through blood and blood products (albeit one that still fell far short of being compensatory in nature).<sup>841</sup> Asked how he came to take this decision (and to do so quickly), Lord Reid told the Inquiry:

*“my recollection is that, well, to put it simply, HIV sufferers had obviously gone through terrible traumas, pain, anxiety, and so on. But so had sufferers from hepatitis C. And you could distinguish – – and I think in documentation it illustrates that people did try to distinguish between those suffering from HIV and those suffering from hep C, HIV tended to be younger, they died quicker, and so on and so forth. But to me, they were people suffering, you know, maybe not identically, but suffering in the same sort of way. The anxiety, the fear, the deaths – – and I didn’t find the distinctions between HIV and hep C sufferers – – it didn’t persuade me that they were justified. Secondly, the cause of that suffering, for both those groups of people, was the same route. It was infection through blood products or blood transfusions supplied by the state. And, thirdly, I wasn’t persuaded by the argument that there is no legal liability. I didn’t believe there was a legal liability but that, in my view, shouldn’t – – the obligations of the state go beyond legal liability. There is a moral compulsion on the state to protect its people ... and when an agency of the state, which is the National Health Service, by its conduct, whether culpable or otherwise, results in the suffering of a lot of people, I thought that they should be treated in a manner that was just. And that’s basically what I remember of my thinking.”*<sup>842</sup>

He told the Inquiry that he did not take this decision on the basis the Scottish Government had done so – rather the decision of the Scottish Government was, he said, the catalyst for prompting these discussions and making him think about it. Lord Reid added “*if the line*

839 Minutes of Scottish Executive and Department of Health meeting 30 July 2003 p1 DHSC0004421\_141. Lord Reid explained in his evidence that “*I wanted a UK scheme and certainly wanted an English scheme, and I was pretty certain that the quickest and best and most coherent way of doing that was for us to do a deal with the Scots and then invite the other two nations to join us, which they did, and they did in very short order.*” Lord John Reid Transcript 21 July 2022 pp41-42 INQY1000232

840 Department of Health Press Release *Hepatitis C Payment Scheme Announced* 29 August 2003 NHBT0015207\_002

841 Lord Reid confirmed in his evidence that once he had taken this decision no official tried to talk him out of it or offer any resistance. Lord John Reid Transcript 21 July 2022 pp28-30 INQY1000232

842 Lord John Reid Transcript 21 July 2022 pp25-26 INQY1000232



*is wrong, you change the line.*<sup>843</sup> He was not troubled by the argument that this would be the slippery slope to no-fault compensation, identifying three factors in his evidence on this point. The first was that the argument “*if you change this, then you might have to change something else*” could be used against any change in policy. The second was that these were to be ex gratia payments, such that “*the argument about the legal liabilities leading to a cascade are overcome.*” The third was that infection with HIV or Hepatitis C through blood, provided by an agent of the state, was “*a sufficiently unique characterisation ... you could circumscribe that as a group.*”<sup>844</sup>

## Commentary

The events described above reveal a deep institutional reluctance within government to, and the lack of an open mind to, the provision of financial support to those infected with Hepatitis C through blood and blood products. A line was adopted, and adhered to for over a decade, for reasons that do not, on analysis, stand up to scrutiny. Those ministers who, from time to time, voiced the wish to make some (albeit limited) provision were firmly steered away from that course by civil servants in the Department of Health.

Three factors predominated in the decision-making of the Department of Health on this issue. The first was the fear that the making of payments to people infected with Hepatitis C would be a major step on the slippery slope to a general system of no fault compensation. The second was the belief that those infected had received the best treatment available at the time, and that there had been no-fault or culpability or mistakes in the way in which they had been treated. The third was the attempt to distinguish the position of those infected with HIV through blood or blood products, from the position of those infected with Hepatitis C through the same route.

The fear that the making of payments to those infected with Hepatitis C would, or might, lead to no-fault compensation more generally was a misplaced one. It was illogical. An action only sets a precedent if the facts are sufficiently similar. The establishment of the Macfarlane and Eileen Trusts had not led to the floodgates opening or to a general no-fault compensation scheme. It was implausible to think that the establishment of a similar scheme for Hepatitis C would do so. If it was necessary to establish a ring fence, that could easily have been done with a scheme where the relevant cohort was those infected through blood, blood products or tissue.

As for the belief that those infected had received the best treatment available, whilst it is understandable why such a belief might predispose ministers against making payments, the difficulty with the Department of Health’s position is that, as set out elsewhere in this Report, it was simply wrong to view the treatment in that light.<sup>845</sup> The Government’s decision making was based on the perception that nothing was done wrong (indeed that everything had been

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843 Lord John Reid Transcript 21 July 2022 p26 INQY1000232

844 Lord John Reid Transcript 21 July 2022 pp26-28 INQY1000232

845 See the chapter on *Lines to Take*.

done right),<sup>846</sup> without there ever having been any comprehensive or balanced investigation into, and assessment of, what had happened. Other ways in which officials and ministers characterised what had happened included “*medical accident*”, “*accepted side effect*”, “*the inevitable risks associated with medical treatment*”. The use of such terms to describe the transmission of viruses with high mortality rates and few if any treatment options<sup>847</sup> was a mischaracterisation of the reality of what had happened. So too was the belief that all patients knew the risks (they did not).

There was no proper basis for saying that those people who were infected by their treatments were given the best possible treatment in the light of available medical knowledge, let alone to say it repeatedly, let alone for over a decade. There was no proper basis for saying that as soon as a screening test for Hepatitis C was available it was put into use. Both these claims assert superlatives. The starting point ought to have been that it was recognised, within the Department of Health, and thus in ministerial briefings, that claims to perfection might possibly be justified but that as a matter of simple human experience they are much more likely to be overstated. Such claims have to be adequately justified. Since it is plain from the earlier chapters of this Report that they were wrong, these claims could never be. Yet they kept on being used to justify not giving those who had been infected with Hepatitis C even the modest sums that were first given through the Skipton Fund.

The attempt to hold the line by distinguishing the position in respect of HIV and Hepatitis C involved the Department of Health in searching for differences<sup>848</sup> rather than dispassionately considering the similarities: those who contracted it from treatment were infected in the same way, from the same sources, with viral conditions that had similar consequences. Both could be debilitating and lead to death. It is plain in any event from the narrative above that those within the Department of Health were well aware of the difficulties of maintaining this distinction. Thus Tom Sackville observed, this was “*a tricky one: if HIV, why not Hepatitis*”,<sup>849</sup> officials in Scotland considered that “*the ‘no-compensation’ position*

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846 As demonstrated by the evidence of Sir John Major: “*not known to anybody that ... nothing anyone could have done that would have prevented it in the light of what was known by science at medicine at the time*”, “*no knowledge that it went wrong*”, “*nobody could have foreseen that*”, “*nobody was derelict in their responsibilities*.” Sir John Major Transcript 27 June 2022 pp192-193 INQY1000219

847 Indeed such treatment options as there were (such as interferon) could be as bad as or worse than the effects of the virus.

848 It was absolutely right, of course, that those infected with HIV in the 1980s experienced the appalling stigma and ostracism that has been so powerfully described in the written and oral evidence provided to this Inquiry. But those infected with Hepatitis C did not escape stigma: it was well known to Government that Hepatitis C was associated with intravenous drug use: see Hepatitis C – The Government’s Response p2 DHSC0002422\_148 (“*Hepatitis C is particularly common among drug abusers*”) and Hepatitis C – Annex C p2 DHSC0032208\_161 (“*The largest group at risk of carrying hepatitis C will be injecting drug users, both current users and those who may have injected drugs in the past*”). There remained echoes of this when the Self-Sufficiency Report was written: the fact that most clinical liver disease came from alcohol was written in to an original draft which contained no allegation of that kind at all, and was in any event about whether imported products caused hepatitis infections, as if to suggest that the real reason why people infected with hepatitis suffered from cirrhosis was that they drank too much, not that they were infected. See the chapter on the *Self-Sufficiency Report*. It could be said that the Department of Health took advantage of the stigma to make points against providing financial relief, rather than taking steps to counter it.

849 Written Statement of Tom Sackville para 8.15 WITN5249001, Memo from Cheryl Cavanagh to Monica Gibson 13 July 1994 p1 WITN5249042

*is becoming increasingly untenable*”;<sup>850</sup> in Wales the view was that “*it would be difficult to sustain rejection of claims for compensation on the grounds of a distinction between those infected with HIV and HCV*”;<sup>851</sup> officials in Northern Ireland thought it difficult “*from point of view of equity to resist comparisons with HIV compensation*”;<sup>852</sup> Departmental officials tacitly recognised in 1996 that the distinction was “*looking increasingly tenuous*”;<sup>853</sup> in 1999 it was described as difficult to explain logically. Rather than face these difficulties, the Government clung to this distinction in the mistaken belief that the sky would fall in – in terms of no-fault compensation – if it did not.

The Government became so fixated on holding that line, maintaining that ring fence, that it lost sight of the desperate circumstances of those whose lives had been and were continuing to be devastated as a result of their treatment by the NHS. The question of moral responsibility (or moral compulsion, to use Lord Reid’s description), and the compelling need for a compassionate response, did not feature in the Government’s thinking until a combination of factors – the campaigning of the Haemophilia Society, of other campaign groups and of individuals, the events in Scotland (themselves the product of the actions of campaigners), the High Court judgment in *A and Others v National Blood Authority*,<sup>854</sup> and a change of Minister to one who was unpersuaded by the Department – brought about a rethink and a change of direction.

That mounting political pressure might eventually render the maintenance of the policy untenable and force the Government to concede was recognised within the Department of Health by the mid 1990s. It should also have been apparent that if Government waited until that point, almost certainly towards the start of the 2000s there would inevitably be individuals who had died, in desperate circumstances and without **any** financial support other than social security (which was not designed to provide for the needs of those with this debilitating illness), in the intervening period.

The fact that it took until 2003 for any form of payment to be announced for those with Hepatitis C and no payment actually to be made until 2004 deprived those individuals, and their families, of support. It prolonged and exacerbated the suffering of those who survived. And it further entrenched deep feelings of injustice.

There is a lesson to be learned from this account. It is that where a government realises that there is a moral compulsion to provide justice for people who have been injured by actions for which it is ultimately responsible it should take immediate steps to provide it. Waiting – for another study, or another day – before doing so adds to the injury. It adds to the hurt. It adds to the numbers who may die without seeing it. It adds to the injustice.

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850 Memo from Paul Pudlo to David Abrahams 5 June 1995 p1 DHSC0004428\_152

851 Memo from Paul Pudlo to David Abrahams 5 June 1995 p1 DHSC0004428\_152

852 Memo from Paul Pudlo to David Abrahams 5 June 1995 p1 DHSC0004428\_152

853 Memo from Paul Pudlo to Charles Dobson 23 April 1996 p2 DHSC0004756\_041

854 Charles Lister described these as the precursors to the ultimate decision to set up the Skipton Fund. Written Statement of Charles Lister para 2.8 WITN4505002

Repeating the errors of the past by waiting, by delaying, to do what seems inevitable should be done, is to be avoided. Delaying when experience shows that payment is inevitable, not only adds to the overall financial costs on the government but leads to loss of the confidence in government and its civil service which it must hope citizens should have, and ultimately comes at a cost to that justice which a state should guarantee to its citizens.

## 6.7 Skipton Fund

This chapter describes the operation of the Skipton Fund, focusing on the particular constraints within which the Skipton Fund operated.

### Key Dates

**29 August 2003** announcements in each of the nations of the UK of financial assistance for people infected with Hepatitis C.

**June 2004** announcement that the Skipton Fund will begin processing applications on 5 July 2004.

**2006** first fund administrator Keith Foster found to have defrauded the Skipton Fund; requirements for documentation from applicants are tightened.

**October 2006** first meeting of the Appeals Panel.

**May 2007** Skipton Fund Agency Agreement is signed.

**2017** Skipton Fund closes and is replaced by the national support schemes.

### People

**Nicholas Fish** administrator, Skipton Fund

**Richard Gutowski** head of blood policy, Department of Health

**Mark Mildred** chair, Skipton Fund Appeals Panel

**Peter Stevens, Elizabeth Boyd** directors, Skipton Fund

**Professor Howard Thomas** medical director, Skipton Fund

On 29 August 2003 John Reid, the Secretary of State for Health, announced that a financial assistance scheme was to be established for people who had been infected with Hepatitis C as a result of being given blood products by the NHS in England. The payments were explicitly *ex gratia*, and the decision was said to be made on compassionate grounds. While “*blood products*” was the term in the press release, the discussion of financial implications in the submission shows the intention was to support people infected through “*contaminated blood transfusions and blood products*.” On the same day there were similar announcements in Scotland, Wales and Northern Ireland by the appropriate minister.<sup>855</sup>

The previous chapter set out a detailed account of the decision-making which culminated (finally) in the decision to establish such a payment scheme. However, readers looking for a short synopsis of what led to this announcement will find one in the next section of this chapter. Later sections explain the remit of the scheme and how it operated.

### Events in Scotland leading to this announcement

This announcement was precipitated by events in Scotland. In 1999, the Haemophilia Society alleged that the NHS in Scotland had been negligent for failing to introduce heat-treated Factor 8 capable of inactivating Hepatitis C until some time after England had done so. The BBC proposed to run a story about these allegations. In August that year word of this reached Susan Deacon<sup>856</sup> who was newly in post as Minister for Health and Community Care in Scotland. She ordered an inquiry into whether people with haemophilia in Scotland had been exposed to unnecessary risk of Hepatitis C through infected blood products in the mid 1980s.<sup>857</sup> This was to be conducted internally within the Scottish Executive.

### Separate developments in England

In separate developments affecting England, in March 2000, a Westminster Hall debate addressed the subject of people infected with Hepatitis C through blood products.<sup>858</sup>

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855 Submission on compensation scheme for Hepatitis C 1 July 2003 p3 DHSC5094083. For the announcements in August 2003, see Hepatitis C Payment Scheme Announced 29 August 2003 NHBT0015207\_002 (England), Hepatitis C payments take a step forward 29 August 2003 DHSC5324002 (Scotland), Minister announces financial assistance for people infected with Hepatitis C 29 August 2003 SCGV0001073\_130 (Northern Ireland), and Assembly Government to look into hepatitis scheme 29 August 2003 p2 SCGV0000255\_035 (Wales).

The Scottish Haemophilia Forum, with good reason, considered that the impetus for the creation of the Skipton Fund came from developments in Scotland. It argued in March 2005 that: “*The Skipton Fund arose only as the result of the campaigning in Scotland by the Scottish Haemophilia Forum, the Motion supported by 80 MSPs from all parties, the unanimous support of the 1999-2003 Health Committee of the Scottish Parliament and the decision of the then Health Minister Malcolm Chisholm.*” It added “*Sadly since then, the work of the Scottish Parliament appears to have been hijacked by Westminster.*” Agenda for Submission from Scottish Haemophilia Forum 1 March 2005 p1 SKIP0000034\_010. The Scottish Haemophilia Forum went on to express unhappiness at aspects of the Skipton Fund: as will be seen from what follows, many of its concerns were justified.

856 Memo from Michael Palmer to PS/Minister for Health and Community Care 5 August 1999 WITN4436004

857 *Report on Hepatitis C* 2001 p10 MACK0001929\_001

858 This was on 7 March 2000. Written Statement of Alan Milburn para 7.9 WITN6942001

Lord Philip Hunt was the Minister with responsibility for blood and blood products within the Department of Health at that time.<sup>859</sup> He met the Haemophilia Society, other groups, patients and their families. These meetings “*were troubling and vividly brought home to me their suffering and the need to help them as much as possible. I looked for ways to do that, but it is a matter of great regret that it took so long for successive Governments to achieve this.*”<sup>860</sup> Following the debate, and also in March 2000, he asked for and received a briefing on options for “*doing more*” for people with haemophilia who had contracted Hepatitis C from their treatment.<sup>861</sup> These focussed on the provision of counselling, but also touched on a hardship fund, analogous to that provided for people with HIV. He was advised that the cost was likely to be unacceptable. Further, the Secretary of State for Health, Alan Milburn, was opposed to a compensation scheme or payments, largely on the basis that they would set a precedent, especially since his view was that no fault had been demonstrated.<sup>862</sup>

### Next developments – mainly in Scotland and in the High Court of England

To return to events in Scotland: in April 2000, the report which Susan Deacon had requested was delivered to her in draft by departmental officials. They sought to steer her “*very firmly in the direction of not agreeing to compensation or special priority treatment for HepC sufferers who may have been infected by NHS treatment*”, keeping in step with her English counterparts.<sup>863</sup>

Such considerations did not trouble the Health and Community Care Committee of the Scottish Parliament, which in June and September 2000 considered the Haemophilia Society petition calling for a public inquiry, and a second petition from a person who did not have haemophilia but who had contracted Hepatitis C as a result of a blood transfusion during a routine operation in 1989.<sup>864</sup> These petitions were to lead the way toward further consideration of compensation.

In 22 October 2000, the Scottish Executive published its report on whether people with haemophilia in Scotland had been exposed to an unnecessary risk of Hepatitis C through infected blood products in the mid 1980s. It found no evidence of fault.<sup>865</sup> However, political pressure mounted. The Haemophilia Society responded that the report was a “*very thin, incomplete piece of work which does not represent the full inquiry we were seeking*”.<sup>866</sup>

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859 Lord Hunt was Parliamentary Under-Secretary of State from July 1999 to March 2003.

860 Written Statement of Lord Philip Hunt para 0.8 WITN4680008

861 Memorandum from Gwen Skinner to Lord Hunt 27 March 2000 DHSC0004033\_003

862 Alan Milburn Transcript 14 July 2022 pp80-83, pp136-139 INQY1000227

863 Email from John Aldridge to Christine Dora and others 19 April 2000 p2 SCGV0000171\_031, Written Statement of Professor Aileen Keel 13 July 2022 pp43-44 WITN5736003

864 Report on Hepatitis C 2001 p9 MACK0001929\_001

865 Report on Hepatitis C and the heat treatment of blood products for haemophiliacs in the mid 1980s October 2000 GGCL0000010. See the chapter on *Government Role and Response*.

866 Letter from Karin Pappenheim to Susan Deacon 27 October 2000 p1 HSOC0011980

The Health and Community Care Committee called Susan Deacon to give evidence on 25 October 2000.<sup>867</sup>

Adding to the pressure, the High Court (in England) judgment in *A and Others v the National Blood Authority*<sup>868</sup> considered claims on behalf of claimants who had suffered Hepatitis C as a consequence of transfusion during NHS treatment. Mr Justice Burton regarded the main issue for his judgment as “*whether the public at large would legitimately expect that different steps would have been taken by way of safety precautions and in particular that: (i) the anti-Hep C assay would be introduced earlier than it was*” and “*(ii) surrogate tests would be introduced in the UK by March 1988*”.<sup>869</sup> In resolving these issues he concluded that routine screening ought to have been introduced by 1 March 1990,<sup>870</sup> and surrogate testing should have been in place by March 1988.<sup>871</sup>

The Secretary of State for Health, Alan Milburn, told the Treasury that the legal advice for the Government was that there was a very limited chance of success and the decision should not be appealed.<sup>872</sup>

A consequence of the court’s ruling was that the Scottish Executive began “*considering constructively the implications*” of it.<sup>873</sup> As a result of this consideration plans developed to enter into discussions in Scotland with Scottish litigants who had been in the same position as those in England and Wales, with a view to settling their actions under the Consumer Protection Act; this was however after Susan Deacon had written unsuccessfully to Lord Hunt to urge the Department of Health/National Blood Authority to seek permission to appeal.<sup>874</sup>

In the meantime, the Health and Community Care Committee of the Scottish Parliament had continued to gather evidence and to consider the petitions before it. In its report published on 3 October 2001, it recommended that the Scottish Executive establish a mechanism to provide “*financial and other appropriate practical support to all hepatitis C sufferers who have contracted the virus as a result of blood transfusions provided by the NHS in Scotland, or which involved blood or blood products produced by the SNBTS [Scottish National Blood Transfusion Service].*” This support should be available “*regardless of whether negligence in the individual case can be proven or not.*”<sup>875</sup>

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867 Report on Hepatitis C 2001 p9 MACK0001929\_001

868 *A and Others v National Blood Authority* Judgment 26 March 2001 PRSE0003333

869 *A and Others v National Blood Authority* Judgment 26 March 2001 para 83 PRSE0003333

870 18 months earlier than it was.

871 *A and Others v National Blood Authority* Judgment 26 March 2001 para 172 PRSE0003333. See the chapters on *Hepatitis C Surrogate Screening* and *Hepatitis C Screening*.

872 No better than 30%. Letter from Alan Milburn to Andrew Smith 5 April 2001 p1 MHRA0025032

873 Written Statement of Susan Deacon 20 April 2022 paras 100-101 WITN4436001

874 Written Statement of Susan Deacon 20 April 2022 para 101 WITN4436001. England and Wales have a unified judicial system; Northern Ireland and Scotland have a separate judiciary. Hence the decision of the High Court was binding on both England and Wales from the start, subject to appeal; but of persuasive value only in relation to Scotland (albeit of powerful force).

875 Health and Community Care Committee Report on Hepatitis C 2001 p26 MACK0001929\_001



The Scottish Executive did not accept the recommendations of the Health and Social Care Committee as they stood, but announced that an expert group, to be chaired by a Court of Session Judge, Lord Donald Ross, was to be set up to look at the pros and cons of a system of financial and other support for those harmed by health service treatment where the NHS was not at fault.<sup>876</sup>

Up until now, the governments of the devolved administrations had adopted the Westminster line that there should be no financial assistance for people who had been injured in circumstances in which the NHS was not at fault.<sup>877</sup> However, it began to emerge that it was likely that Lord Ross' expert group would call for financial help. In September 2002, Lord Ross presented preliminary recommendations to the Scottish Executive. He proposed initial lump sum payments and a discretionary trust making ex gratia payments to all those who had probably received blood, blood products or tissue from the NHS in Scotland and who had become infected with Hepatitis C.<sup>878</sup> Scottish ministers felt they should offer something. Alan Milburn, thinking this a grave mistake and a slippery slope, sought to persuade Malcolm Chisholm, the Minister for Health and Community Care, not to proceed with any announcement to this effect in Scotland.<sup>879</sup> There now began a disagreement between the UK Government and the Scottish Executive as to whether making payments to relieve financial hardship arising out of health care treatment was a matter in which the Scottish Executive had any right to legislate: it was thought it might not be a devolved issue and that if it were not, it would not be within the competence of the Scottish Executive to consider it.<sup>880</sup>

Although the Scottish Executive considered that the levels of financial assistance recommended by Lord Ross were too high, Malcolm Chisholm made it clear to Westminster that he wished to introduce a payment scheme. On 29 January 2003 he said he would make £20,000 available for those diagnosed with Hepatitis C, with a further £25,000 paid to sufferers who developed conditions such as cirrhosis and cancer of the liver.<sup>881</sup> As *The Scotsman* promptly reported, this put him “on a collision course with Westminster which has ruled out making payments south of the Border. Now the Department of Health is expected to obstruct payments in Scotland, arguing that the Executive does not have the power to make such decisions.”<sup>882</sup>

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876 The announcement of an expert group was made in December 2001, with the expert group under Lord Ross being established in March 2002. Executive to look at future health compensation system 11 December 2001 SBTS0000358\_040, Parliamentary Question by Lord Alf Morris of Manchester 2 September 2003 p19 DHSC0006217\_027

877 See the chapter on *Northern Ireland and Wales*.

878 Preliminary Report by The Expert Group on Financial and Other Support September 2002 pp10-11 HSOC0003349

879 Email from Sammy Sinclair to Charles Lister 4 November 2002 DHSC0042275\_129

880 Submission from Charles Lister on Hepatitis C Scottish Compensation Proposals November 2002 WITN4505036, Parliamentary Question by Lord Alf Morris of Manchester 2 September 2003 pp19-20 DHSC0006217\_027

881 Scottish Executive Proposal For Ex Gratia Payment Scheme [Hepatitis C from Blood] 29 January 2003 p2 SCGV0000251\_018

882 Email chain between Charles Lister and Civil Servants 30 January 2003 pp5-6 DHSC5110387

The question of legislative competence then had to be resolved. By the summer of 2003 it became clear that the question of whether to introduce a compensation scheme as proposed by Lord Ross was within the competence of the Scottish Executive to determine.<sup>883</sup> A significant change also occurred in England. Dr John Reid (later Lord Reid) became Secretary of State in June in succession to Alan Milburn. Although he was advised by the civil servant who had principal responsibility at the time for blood and blood policy, Richard Gutowski, that financial assistance for people infected with Hepatitis C through blood or blood products was not justified,<sup>884</sup> Dr Reid developed a firm view that a scheme to provide financial assistance was the right thing to do.

Thus it was that on 29 August 2003 it was announced in each of the nations of the UK that a financial scheme to support those who had been infected with Hepatitis C as a result of their treatment by infected blood, blood products or tissue would be established. The detailed proposals emerged a little later. It is to the story of how, bit by bit, the parameters of the scheme were established that this account now turns.

## Parameters of the Skipton Fund

A few weeks before the announcement, a meeting was held between the civil servants who were progressing the scheme on behalf of the Scottish Executive, and their counterparts from the Department of Health.<sup>885</sup> It was envisaged at that stage that:

*“Those qualifying would receive a £20,000 payment, followed by a further £25,000 should their disease progress to a medically defined trigger point ... [People coinfecting with HIV] would be eligible to claim the £25,000 award should their condition progress to the trigger point. Eligible patients who cleared the disease spontaneously (approx 20%) would receive no payments, those who cleared after treatment would receive the £20,000 payment only and those who receive a liver transplant would receive both awards.”<sup>886</sup>*

If this had been applied, then anyone who cleared at any stage, but had not had treatment (often described as a “natural clearer”), would not receive any payment.

Following the Secretary of State’s agreement to the various component parts of the scheme,<sup>887</sup> a Scottish intervention threw into doubt payment for people who had cleared Hepatitis C following treatment.<sup>888</sup> The Haemophilia Society had also stated that “*they could*

883 Parliamentary Question by Lord Alf Morris of Manchester 2 September 2003 p13 DHSC0006217\_027

884 Written Statement of Lord John Reid para 8.3 WITN0793001, Memo from Richard Gutowski to Sammy Sinclair 17 June 2003 DHSC5320518, Email from Sammy Sinclair to Vicki King 17 June 2003 DHSC5541406

885 Those present at the meeting on 30 July 2003 were Andrew MacLeod and Bob Stock, from the Scottish Executive, and Richard Gutowski and David Reay, from the Department of Health. Notes of Scottish Executive and Department of Health meeting 30 July 2003 DHSC0004421\_141

886 Notes of Scottish Executive and Department of Health meeting 30 July 2003 DHSC0004421\_141

887 Letter from Richard Gutowski to the Secretary of State 3 October 2003 p2 DHSC0016672, Email from Richard Gutowski to Nicola Hewer 3 October 2003 DHSC5326827

888 Email from Bob Stock to Richard Gutowski 10 October 2003 SCGV0000256\_071

*not accept*” such a scheme and the Secretary of State agreed that there should be further discussion with the Society and Macfarlane Trust.<sup>889</sup>

Initial discussions led to a response from the Haemophilia Society which, as well as conveying the Society’s overall disappointment with the actual sums of money to be offered, expressed four outstanding concerns about the scheme as then proposed: that people co-infected with HIV were to be excluded until the onset of cirrhosis; that bereaved dependants of an infected person who had died would get nothing; that people suffering advanced liver disease without cirrhosis would not receive the higher payment; and that people who had cleared HCV following treatment were not eligible.<sup>890</sup>

This in turn was followed by a plea direct to the Department of Health from Dr Paul Giangrande<sup>891</sup> who had been part of a working group which had produced a report about an appropriate payment scheme for the Haemophilia Society in June 2002.<sup>892</sup> He said they “*strongly felt that some form of payment should be made to patients who have simply tested positive for the HCV antibody, even if they subsequently cleared this and did not have abnormal liver function tests*”; that it was “*grossly unfair*” that people coinfecting “*should not receive additional compensation*”; and that “*Equally, we feel it grossly unfair that compensation should not be offered to the relatives of those who died from hepatitis*”.<sup>893</sup>

*The Guardian* in an article on 29 October 2003 added its weight to these influential pressures, focussing its support on the first two concerns the Haemophilia Society had raised,<sup>894</sup> and Michael Connarty MP, chairman of the All-Party Group on Haemophilia, then met the Parliamentary Under-Secretary of State for Public Health, Melanie Johnson. As a result of that meeting, she asked her civil servants to estimate the costs of extending the proposed scheme to cover people who were coinfecting, those who had cleared Hepatitis C following treatment, and dependants.<sup>895</sup> On 10 November 2003 Richard Gutowski responded to the Minister by recommending that both the first two of these groups be made eligible; but that extending the scheme to dependants “*would at least double the cost of the scheme and remains unaffordable within the existing budgets of all the four Health Departments*.”<sup>896</sup> His

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889 Letter from Richard Gutowski to the Secretary of State 3 October 2003 p2 DHSC0016672, Email from Richard Gutowski to Nicola Hewer 3 October 2003 DHSC5326827

890 Karin Pappenheim expressed these in a letter of 17 October to Richard Gutowski giving the Society’s formal response to the discussions she had had that week. Letter from Karin Pappenheim to Richard Gutowski 17 October 2003 DHSC0004520\_002. She said that unless they were resolved the Society could not support the scheme.

891 Director of the Oxford Haemophilia Centre.

892 Report of the Hepatitis C Working Party to the Haemophilia Society June 2002 HSOC0005927. There were seven members of the group, including three haematologists and the chairman of the Personal Injuries Bar Association.

893 Letter from Dr Paul Giangrande to Dr Hugh Nicholas 24 October 2003 DHSC0004421\_005

894 *The Guardian Families ‘excluded from hepatitis payouts’* 29 October 2003 HSOC0015031\_013

895 Memo from Richard Gutowski to Parliamentary Under-Secretary of State for Public Health 10 November 2003 p1 DHSC5328495. Further reinforcing the plea for an expansion of eligibility for the scheme, Peter Stevens also wrote with suggestions. Email from Peter Stevens to Richard Gutowski 3 November 2003 DHSC5328195

896 Memo from Richard Gutowski to Parliamentary Under-Secretary of State for Public Health 10 November 2003 pp1-2 DHSC5328495

submission showed that initial estimates had included people who were coinfecting and those who had cleared Hepatitis C following treatment so their inclusion would not involve any additional cost to that already budgeted.

By December the Secretary of State confirmed that he was content that both people who were co-infected, and those who had cleared the virus after treatment, should be included in the scheme.<sup>897</sup> The parameters as then proposed were confirmed in a submission to the Secretary of State on 6 January 2004 and announced on 23 January 2004.<sup>898</sup>

The position on natural clearers was “*No payments to those who have cleared the virus spontaneously*”<sup>899</sup> but this was changed after a personal intervention by an individual, in an email addressed to Richard Gutowski, in early February 2004. This described how the writer had cleared the virus without treatment, but had carried it in a chronic active state for some 20 years.<sup>900</sup> The email said:

*“All its illnesses, the loss of income, the loss of the possibility of gaining any kind of life insurance, the loss of company pension, the stigma that surrounds this infection, The mental stress and worry that came with it for both myself and my family, and the fact that I had to move home because of my fears for my families safety ... All doctors in this field who I have spoken with have stated that ... it is likely that because of the long period of time I was carrying this virus in it’s active form, I am likely to have sustained some liver damage. Could you clarify, if someone like myself will be included or excluded from this payment?”*<sup>901</sup>

The civil servants sought medical advice from within the Department of Health, which said it was feasible that he had cleared the virus even after 20 years. This prompted a rethink, to leave the way open “*for those who have cleared the virus way down the line, such as [the author of the email].*”<sup>902</sup> This personal intervention thus succeeded where other efforts had not.<sup>903</sup> A press release on 3 June 2004 announced that the Fund would begin processing applications on 5 July 2004 and it confirmed that people who had cleared the Hepatitis C virus spontaneously “*after a period of chronic infection*” would be covered by the scheme.<sup>904</sup>

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897 Email from Robert Finch to Richard Gutowski and others 9 December 2003 DHSC5977779

898 Hepatitis C financial assistance scheme – Announcement of details 6 January 2004 p4 DHSC0016663, Details of Hepatitis C ex-gratia payment scheme announced 23 January 2004 WITN5292025

899 Hepatitis C financial assistance scheme – Announcement of details 6 January 2004 p4 DHSC0016663

900 From the mid 1970s to mid 1990s.

901 Email chain between David Reay and Richard Gutowski 3 February 2004 p2 DHSC5331957

902 Email chain between David Reay and Richard Gutowski 3 February 2004 p1 DHSC5331957

903 Including those of Dr Giangrande and the UK RCN Haemophilia Nurses Association. Letter from Dr Giangrande to Dr Nicholas 24 October 2003 DHSC0004421\_005, Letter from Chris Harrington to Richard Gutowski 16 October 2003 HSOC0003258

904 Letter from Richard Gutowski to Karin Pappenheim 18 June 2004 p1, p4 HSOC0016815

## The structure of the scheme

The Skipton Fund, as the scheme was called, differed from the two grant-giving charities (the Macfarlane Trust and Eileen Trust) in that it was not a trust, but set up as a corporation. Nor was it charitable as such. Nor was it independent of the Department of Health: it was set up specifically as an agent of the Department of Health. Nor was it dealing with HIV infection and its aftermath, as both Macfarlane and Eileen were. Its focus was Hepatitis C. Being set up formally as neither a charity nor a trust, it had a board of directors, not trustees. A further and important point of distinction was that appeals against the refusal of an application were not addressed internally to the same body as had made the determination, as happened in the Macfarlane Trust, but to a body set up to be independent of the Skipton Fund and, it follows, of the government. Though Nicholas Fish, who was for most of its time in operation the administrator of the Fund, provided support to the Appeals Panel, this role was administrative only and was neither advisory nor decision-making in nature.

Though the Skipton Fund began operations in 2004,<sup>905</sup> the Agency Agreement under which it operated was not finalised until the first version of it was signed on 22 May 2007.<sup>906</sup> Though this was described as an “*agreement*”, it was open to the Department to make changes to its terms should it wish to do so<sup>907</sup> because the essential relationship between the Skipton Fund and government was that of agent and principal.<sup>908</sup>

The Skipton Fund operated on a UK-wide basis until its closure in 2017, when its functions were transferred to separate blood payment schemes administered by the respective nations.<sup>909</sup>

### Administration of the Fund

A secretary and administrator ran the Skipton Fund, supported in part by a financial team shared with other Alliance House Organisations.

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905 It was incorporated on 25 March 2004 as a private company limited by guarantee, and as noted in the text began processing applications as from 5 July 2004.

906 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 SKIP0000033\_066. The length of time it took for this to happen (especially since it is difficult to see why it depended on the consent of the Skipton Board, when the role of an agent is to act in accordance with the wishes of its principal) was never satisfactorily accounted for.

907 A number of such changes occurred.

908 When the Caxton Foundation was set up in March 2011 one of its first challenges was identifying those who were eligible for awards under its founding document. Only those who were eligible for Skipton funding were eligible. As set out in the chapter on the *Caxton Foundation*, this relationship of principal and agency under which operated should have facilitated applications to the Caxton Foundation by those who were eligible and in need of specific financial support, but the Department of Health did not initially facilitate this.

909 For the Skipton Fund, the Department of Health acted on behalf of the devolved administrations in accordance with a service level agreement. The four nations then set up the England Infected Blood Support Scheme (“EIBSS”), the Scottish Infected Blood Support Scheme (“SIBSS”), the Infected Blood Payment Scheme for Northern Ireland (“NIBSS”), and the Wales Infected Blood Support Scheme (“WIBSS”).

## Payments by the Fund

There was no discretion as to the amount to be paid. “Stage 1” lump sum payments, initially of £20,000, were made to applicants who could prove on the balance of probabilities that they had *“contracted the hepatitis C virus because of receiving blood, blood products or tissue from the NHS prior to September 1991 or, in certain circumstances ... from a person who has received such treatment.”*<sup>910</sup> This expressly included everyone with haemophilia who had *“developed”* Hepatitis C after being treated with Factor 8 or Factor 9 concentrates, cryoprecipitate or Factor 8 inhibitor bypass activity (“FEIBA”) or plasma (including fresh frozen plasma) or anyone treated with whole blood or any blood component, albumin, bone marrow, intravenous immunoglobulin, or *“DEFIX”* Factor 9 concentrate.<sup>911</sup> A person was eligible whether or not also infected with HIV.

A further “Stage 2” lump sum of £25,000 was payable to a qualifying person who *“has an advanced stage of illness due to hepatitis C virus because of receiving blood, blood products or tissues from the NHS prior to September 1991. In this context, persons with cirrhosis or primary liver cancer and those who have received, or are on the waiting list to receive, a liver transplant are eligible to apply.”*<sup>912</sup>

The issues which took centre stage for the Inquiry were those of qualification for these two payments. Qualification for Stage 1 payments was a necessary step not only towards receiving such payments but also towards qualifying for Stage 2 payments. Whereas refusal of an application for a Stage 1 payment precluded any payment, a refusal for a Stage 2 payment was much more a “not yet” decision, since it was likely to be on the basis that though the applicant’s liver had deteriorated it had not yet done so to the degree necessary to trigger the payment. Thus this chapter looks first at general qualification for any payment, before considering access to Stage 2.

### *Qualification for a Stage 1 payment*

Not every person infected with Hepatitis C from blood, blood products or tissue as set out above was eligible. A *“qualifying person”* had to have been alive on 29 August 2003 and to have been treated before September 1991.<sup>913</sup> People who acquired Hepatitis C but had also *“spontaneously cleared the virus in the acute stage”* and never developed chronic Hepatitis C infection were also ineligible for payments.<sup>914</sup> Though a common understanding

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910 Definition of a Stage 1 payment. Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 p5 SKIP0000033\_066

911 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 p23 SKIP0000033\_066. Because a person may be infected with a virus, rather than *“develop”* it, the Agency Agreement was describing developing symptoms or signs of infection by Hepatitis C ie consistent with more than having the virus in the bloodstream.

912 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 pp5-6 SKIP0000033\_066

913 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 p25 SKIP0000033\_066

914 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 p23 SKIP0000033\_066

of acute illness may be that what makes it “acute” is that its symptoms are particularly severe, in this context “acute” is not linked to “severity”. It is defined by time. An infection is “acute” for six months after which it becomes “chronic”, even if the symptoms during those first six months are mild or even not apparent at all.

The way the scheme was drafted, the burden of proof that an infection had become chronic rested on the applicant.

People were also eligible if, on the balance of probabilities, they became infected by transmission of the virus from a qualifying person. This applied if, at the time of transmission, the person infected was a spouse or civil partner, cohabitant, mother, or son or daughter of the mother from whom the virus was transmitted. The infection must have occurred as a result of sexual transmission, transmission from mother to baby, accidental needle stick injury (limited to the relationships set out, and excluding shared drug use) or by some other route verified by a medical practitioner, again within the relationships set out.<sup>915</sup>

The estate of a person who had died after 29 August 2003 could make a claim in respect of the infection of that person. There was nothing in the documentation to say that that person must have died wholly or partly because of Hepatitis C. However, until 12 January 2006 no payment could be made in respect of any person who had died after 29 August 2003 but before 5 July 2004.<sup>916</sup>

Those bereaved by the death of a qualifying person had no claim as such: they would receive only their entitlement, if any, under the deceased’s estate.

It should be noted that qualification for, and the amount of payment to be made, did not depend on any assessment of the severity of the effects of their infection, apart from whether the applicant had cirrhosis for Stage 2. Though the consequences of infection, generally, were what led to ex gratia payments being thought appropriate, no distinction was made, save as between Stage 1 and Stage 2, between those more seriously affected physiologically, nor any account taken in the scheme itself as to the presence or degree of psychological distress, social or financial disadvantage that resulted.<sup>917</sup>

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915 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 pp23-24 SKIP0000033\_066

916 The dates respectively of the announcement of the Fund and its beginning operation. The estates of people who had died prior to August 2003 only became eligible in 2011. Statement on Blood and Blood Products 10 January 2011 p2, p4 ARCH0001703

917 Bob Stock, the head of Ancillary Services Branch, Health Planning and Quality Division (Scottish Executive), in due course suggested press lines to be adopted which included “*Ministers have made it clear from the outset that the scheme would only make payments to patients who had experienced lasting physiological harm as a result of their infection.*” Spontaneous Clearance of Hepatitis C p2 DHSC0011630. This appears to be the basis for Dr Ailsa Wight (who was since April 2004 deputy director of Infectious Diseases and Blood Policy, Department of Health) saying in a written statement in 2010 that “*There are no written Departmental records available of any discussions at around that time, on the issue of whether payments under the proposed scheme should cover ongoing psychological damage if it occurred after clearance in the acute phase. However records from November 2004 state that the policy from the outset was that no account would be taken of any pain, discomfort, loss of earnings etc incurred in the past (ie, during the acute phase), or of psychological damage or social disadvantage continuing after they had cleared the virus.*” Written Statement of Ailsa Wight for *R v Skipton Fund and Secretary of State for Health* p5 WITN4509004

## Application process

In order to apply, the applicant first had to complete an online registration form, providing contact details, bank details and details of any registration at a haemophilia centre. A paper form would then be sent out. This had to be completed by the applicant's "*Hospital Doctor or General Practitioner*". The purpose was to "*confirm that the patient has been chronically infected*" and also "*that the infection most probably arose through treatment with NHS blood or blood products*".<sup>918</sup> There was therefore no opportunity in the application form or process for applicants to provide any direct evidence themselves as to whether they had received blood or blood products prior to September 1991.<sup>919</sup>

The scheme administrator would determine whether the application form had been completed sufficiently (if not, it would be returned to either the applicant or completing clinician) and then either they or one of the directors would determine whether it was successful. No payment was made without the signature of a director.<sup>920</sup>

Part of the reason for this process was that the first administrator of the fund, Keith Foster, was found in 2006 to have defrauded the Fund of some £400,000. After that, security checks were strengthened. Applicants had to provide both (a) their NHS numbers to check that they actually existed as real people, and (b) copies of medical records confirming both their Hepatitis C status and that they had received contaminated blood or blood products within the NHS prior to September 1991. A check was made to see that the doctor's signature was genuine, and a requirement was imposed upon a successful applicant to furnish a signed receipt. Martin Harvey, who was a director of the Skipton Fund as well as chief executive for the Macfarlane Trust, would carry out random checks.<sup>921</sup>

The consequence of this was that a heavy emphasis was placed upon having records available to show that an individual had received a blood transfusion from which, in the absence of other more likely sources, that person had become infected with Hepatitis C.

Though it was the dishonesty of an employee of the Skipton Fund which led to these precautions, and there had been no criticism of the integrity of any applicant, the result was significant additional hurdles for all applicants to overcome. This was on top of the

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Both these statements are not wholly accurate: account of disadvantage undoubtedly inspired the scheme in the first place, though eligibility was on the basis of chronic infection, or the development of cirrhosis, rather than any other individual consequences whether physiological or psychological. To eliminate the psychological loses sight of this, and also does not take account of the fact that one of the principal complaints of those infected was that they suffered "brain fog", loss of sleep with all its consequences, and the worries that came with that and with infection itself. The later statement in particular looks to resist a claim for greater compensation on the basis of the policy that inspired the ex gratia relief schemes in the first place, yet it is, as Ailsa Wight acknowledges, impossible to find any clear contemporaneous statement of policy to the effect that the original scheme was introduced without any idea that psychological consequences (however described) were to be ignored as part of the reason for the scheme in the first place. A "line to take" is not to be equated with a statement of policy.

918 Counsel Presentation on Skipton Fund 22 March 2021 p9 INQY0000245

919 Skipton Fund blank application form for first stage ex gratia payment SKIP0000023\_107

920 Counsel Presentation on Skipton Fund 22 March 2021 pp9-10 INQY0000245

921 Skipton Fund Administrators Report 30 April 2007 pp2-4 SKIP0000031\_163



difficulties people already experienced from Hepatitis C, including (for example) brain fog and excessive tiredness.

## Applications accepted and rejected

The following picture emerges from the papers available to the Inquiry:

	Number of Cases <sup>922</sup>
<b>applications for a Stage 1 payment</b>	6,712
<b>total applications approved</b>	5,529
approved by the Skipton Fund	5,309
declined by the Skipton Fund and not appealed	622
declined by the Skipton Fund and appealed	443
of those appeals: approved	220
of those appeals: declined	223

It follows that around one fifth of applications were declined; around 80% succeeded. There were a number of reasons why applications were declined.<sup>923</sup> The principal reasons were that the individual was a “natural clearer” (at least 200<sup>924</sup> of those initially declined); that there was a lack of evidence of transfusion and/or lack of medical records (which had been destroyed or were unavailable); that there had been, or was thought to have been, intravenous drug use, and to a lesser extent, that the implicated blood product or transfusion occurred after 1 September 1991. There was a handful of other reasons, none of which occurred in any substantial number: anti-D (an immunoglobulin used to prevent Rhesus disease) injection; the source of Hepatitis C was not NHS blood or blood products; needlestick injury; the infection was not Hepatitis C; the transfusion had occurred overseas; the transmission was by sexual intercourse or it came from being tattooed; or there was a problem with the application form or with time limits.

Of those declined both by the administrator and on appeal, the reasons given for refusing the application differed in nearly a fifth of the cases as between the Fund and the Appeals

922 Counsel Presentation on Skipton Fund 22 March 2021 p15, p18 INQY0000245

923 In the course of the Inquiry a presentation was made by Counsel which set out a chart of these reasons. Counsel Presentation on Skipton Fund 22 March 2021 INQY0000245. It was drawn from a study of 314 files which had been declined. They had come from box files held by the Fund. In evidence, Nicholas Fish was asked about why applications had been rejected. He said about a quarter of the rejections had been because of the absence of medical records, and then added: “*About half [the rejections] are natural clearers. In fact, I noticed in your numbers [he had seen the presentation figures] you might be missing three lever-arch folders’ worth of natural clearer rejections. The solicitor should have those if you request them. They were stored in lever-arch folders instead of box files. So that was half of the declines were natural clearers, then about a half again, or maybe slightly more than half, were a lack of evidence of a probable transfusion and then the other quarter would have been other reasons: IV drug use, anti-D, et cetera.*” Nicholas Fish Transcript 23 March 2021 pp96-97 INQY1000111

924 Approximately one third.

Panel.<sup>925</sup> This was accounted for by an increase in the number declined because of a lack of evidence of receipt of a transfusion or blood product, and an almost corresponding decrease in the number declined because medical records were destroyed or unavailable; broadly, the other reasons remained the same.

## Problems in qualifying for payments

The first problem is a lack of knowledge. When the Fund was first established in 2004, many potential applicants would not have realised that they were infected with, and were suffering from symptoms of, Hepatitis C.<sup>926</sup> The insidious nature of the disease, with symptoms evolving only slowly over time, of a non-specific type when seen in isolation, saw to that. To claim, they would have to be aware, too, of the possibility that a transfusion might have been the cause of their infection. They would not necessarily draw a link between events some 20 or even 30 years before and a diagnosis only recently made, and their GP may well have attributed a diagnosis of hepatitis to alcohol or a fatty liver, or “lifestyle choices” rather than a transfusion. The only evidence there had been a transfusion might have been the patient’s recollection: there might well have been no record of it; if so, a doctor consulted by someone infected would have nothing particular to prompt her or him to ask the patient if she or he had ever had a transfusion.

Those who were aware (a) that they had Hepatitis C, and (b) that they might have been infected by transfusion or transplant, may then have been inhibited by some of the criteria for application. They had to have been infected prior to September 1991. They may have been deterred by the application process. It did not allow, in the first instance, for them to set out their own account. An application form had to be completed by their doctor, except for brief personal details supplied by the applicant. This not only meant that the clinician had to be satisfied that the transfusion was likely to be the cause of the hepatitis infection which had become apparent, but had (after the early stages of the Fund, and after the fraud of the first administrator) to provide records which showed there had been a transfusion.<sup>927</sup> The patient would not routinely be shown a copy of what the clinician had to say. Applicants had

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925 The reason an application was declined by the Appeals Panel differed to the decision by the Skipton Fund in 41 of 218 cases reviewed (19%).

926 It is clear that less than one quarter of those who were probably infected as a result of treatment have made a claim. There has been no comprehensive study of the reasons for this and it would in any event be difficult to make, since researchers could hardly be expected to approach people who did not know they had been infected, had put their symptoms down to some other cause, or who, if infected, had not realised that the infection might well be, and perhaps probably was, the consequence of a transfusion a number of years ago. The main reason will have been people’s deaths: some 80% of those estimated to have survived to 10 years after transfusion made a claim. The Statistics Expert Group compared the age-sex bands for EBISS claimants in England against their estimates and identified three groups who appear to be underrepresented: women born 1945-1964 who had a transfusion around childbirth (just over half the number estimated feature as claimants); people born 1965-1974 (only a third of the number estimated feature as a claimant); people born 1975-1984 who had a transfusion as a child (at best a quarter feature as claimants). Expert Report to the Infected Blood Inquiry: Statistics September 2022 p8 EXPG0000049, Expert Report to the Infected Blood Inquiry: Statistics (Supplementary) July 2023 p9 EXPG0000132

927 Counsel Presentation on Skipton Fund 22 March 2021 p12 INQY0000245

to be alive on 29 August 2003, and (at least initially) to have applied for payment from the Skipton Fund during their lifetime, if their estate was to have any claim.<sup>928</sup>

To suffer from “hepatitis” as a consequence of treatment was insufficient. Hepatitis B was excluded. This exclusion is particularly unfair. It persists in the national support schemes to this day. The reason for this was articulated by William Vineall in his evidence: “*we think the testing regime that was established, I think in about 1972, for hepatitis B was sufficient to ensure that people with hepatitis B wouldn’t be, you know, subject to the risk of infected blood, and that’s why it’s never been part of any scheme*”.<sup>929</sup> It is certainly right that in 1972 blood donations were first screened for Hepatitis B throughout the UK. However, the screening tests used then were imprecise,<sup>930</sup> and there is ample evidence from the literature and from the evidence before the Inquiry, that Hepatitis B not infrequently continued to be transmitted by blood at least until the early 1980s when screening tests became much improved.<sup>931</sup> Moreover, the availability of screening was not the only precautionary measure. Avoiding unsatisfactory or risky donors was another.<sup>932</sup> So too was ensuring that transfusions were given only when needed,<sup>933</sup> and then only in no greater quantity than actually required. When a person developed Hepatitis B after a transfusion, there could and should have been a check back to see from whom the donation had come. Records were frequently inadequate for this purpose, or were missing.<sup>934</sup> Considerations such as these are persuasive of the need for any sufficient scheme to include support for those with Hepatitis B as a result of their treatment.<sup>935</sup>

Another exclusion from potential benefit was the limitation to NHS treatment. In the 1970s and 1980s many members of the armed forces served abroad, and they and their families were entitled to the benefit of treatment by military hospitals which were under UK control.

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928 Counsel Presentation on Skipton Fund 22 March 2021 p7 INQY0000245

929 William Vineall Transcript 21 May 2021 p145 INQY1000121. William Vineall has been Director of NHS Quality, Safety and Investigations at the Department of Health and Social Care since 2016.

930 Initially these were by immunoelectro-osmophoresis (“IEOP”), then by counter-immunoelectrophoresis (“CEP”), or reverse passive haemagglutination (“RPHA”). They were thought to have a sensitivity of around 30%, as reported by a World Health Organization Scientific Group in 1973: “*The present widely employed techniques for detecting hepatitis B antigen in blood are thought to be capable of preventing approximately 30% of cases of post-transfusion hepatitis.*” World Health Organization Technical Report Series Viral Hepatitis: Report of a WHO Scientific Group 1973 p17 SCGV0000204\_073. In 1975, radioimmunological assay (“RIA”) began to be used with greater sensitivity, though still missing around one third of infections, and further refinements followed into the early 1980s. Second Report of the Advisory Group on Testing for the Presence of Hepatitis B Surface Antigen and its Antibody September 1975 p6 CBLA0000313. See also: Alter et al *Clinical and serological analysis of transfusion-associated hepatitis* The Lancet 1 November 1975 p1 PRSE0001172. Dr Harvey Alter and his colleagues said: “*the attainment of hepatitis-free blood-transfusions has been a frustratingly slow, but progressively realistic goal.*”

931 See the chapters *Knowledge of Risk Before 1970* and *Hepatitis Risks 1970 and After*.

932 See the chapter *Response to Risk by the Blood Services*.

933 See the chapter *Blood Transfusion: Clinical Practice*.

934 Counsel Presentation on Early Lookback Investigations October 2021 INQY0000310

935 For the Inquiry’s recommendations about the parameters of future financial support and compensation regarding Hepatitis B infections see the Inquiry’s Report on Compensation. Infected Blood Inquiry Second Interim Report 5 April 2023 pp28-33, p94 INQY0000453

Whether they qualified was for a while uncertain, but was later clarified through appropriate wording being added to the scheme.

### **First issue: did the applicant have a qualifying infection?**

This may seem a simple, medical question. In many cases it was, once there was a reliable test for infection with Hepatitis C. But in two particular cases an infection did not qualify for further consideration, whatever its cause might be.

#### *(1) The “cut-off” date*

A “bright line rule” (such as that in relation to the date of 1 September 1991 for the Skipton Fund) is often desirable. It may make for administrative efficiency. It is easy to understand by those subject to it, even if they may not like the result. It makes for consistency between would-be applicants.<sup>936</sup> It means, however, that the deserving but exceptional case has no remedy. That is the inevitable result of falling on the wrong side of the line, no matter how much it might generally be agreed that a case has individual merit. That is why many “bright line” arrangements also allow for some discretion to be used to permit the truly exceptional case to succeed. The Skipton directors should have been allowed to exercise discretion for the truly exceptional case. Screening will pick up viral loads only beyond a threshold minimum. In the early stages of incubating a virus, that threshold might not have been reached. If screening for Hepatitis C occurred at that time, it would not reveal the lurking infection and the donation would be accepted. A virus in a donation made during this “window period” would then continue to incubate and to replicate. If the blood donation in which it does this is then transfused, it may then manifest itself eventually in infection. One way of trying to avoid it is ensuring that a “quarantine period” should be allowed for, but the scope for this is limited since blood for transfusion as such has to be used within six weeks at the outside.<sup>937</sup> Further, organs and tissue for transplant were not so easily and readily screened as was blood; and a secondary transmission from someone infected within the period that resulted in a later diagnosis should have, but did not, come within the scheme. A “bright line rule” excluding any donation made after 1 September 1991 as a cause of a person’s Hepatitis C could not accommodate such a case, however deserving it might be.<sup>938</sup>

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936 Avoiding what truly is inconsistency is integral to fairness.

937 For this reason, it was suggested early in the life of the Skipton Fund that a period of 35 days after 1 September should be allowed by the scheme administrators, but this (a) was never made an official exemption by authority and (b) if it had been it would have concerned only those donations where the infection was “brewing” as at 1 September. It would not cover those donations which were made later and were not picked up by a screening test, because they had occurred during a “window period.” This was explained in the lines to take about the Skipton Fund used in June 2004, in a template letter for queries about why homosexual men could not donate blood: “*Current screening tests for blood still fail to pick up people with very early infection. This is called the window period when people with HIV have not yet developed markers of HIV infection. We are also concerned about viral hepatitis (hepatitis B virus and hepatitis C virus). Advances in technology and science are helping to reduce this significantly, but it is still a risk.*” Department of Health Blood Policy on Hepatitis C Ex-Gratia Financial Assistance Scheme 22 June 2004 p6 DHSC0041181\_002

938 For the Inquiry’s recommendations about the parameters of future financial support and compensation regarding the cut-off dates for infection, see the Inquiry’s Report on Compensation. Infected Blood Inquiry Second Interim Report 5 April 2023 pp33-35, p94 INQY0000453

(2) “Natural clearers”

Whether a person qualified for relief under the fund had to be determined by the administrator and his team and one of the directors.<sup>939</sup> The first question was (a) whether the applicant was infected with Hepatitis C; and (b) whether the cause of that infection was “*receiving blood or blood products from the NHS*”.<sup>940</sup> In addressing the first of these questions it was not enough to ask if applicants “had ever been infected”, for as a result of the changes made as the outline scheme moved towards implementation it was, rather, “have they been infected for longer than 6 months after the relevant treatment?”<sup>941</sup>

Self-reports of symptoms consistent with hepatitis which had lasted more than six months might also be consistent with a number of other conditions, whether temporary or more permanent: but the Skipton application form did not provide any space for applicants themselves to explain what they had suffered, and why they related it to a transfusion or blood product. Situations such as this call for careful review. This suggests a case-by-case consideration. It also calls for a detailed account by the applicant to explain why the infection (as they see it) lasted beyond six months.

Unfortunately, it seems that on first looking at an application in the Skipton office it was often the case that broad generalisations were applied rather than individual focus brought to bear on a particular case. Too heavy a weight was placed on there being a clear indication in medical records that the applicant had shown signs and suffered symptoms<sup>942</sup> after six months from the presumed date of first infection. Some applications were thus most probably rejected because of what tended to be a “one size fits all” approach. It was, perhaps, easier to assume that the medical advice that in general most people who cleared did so within the first six months of infection was applicable to all.<sup>943</sup>

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939 Counsel Presentation on Skipton Fund 22 March 2021 p9 INQY0000245

940 The expression “*receiving blood or blood products from the NHS*” has the effect of including products which were supplied by the NHS but not of NHS origin, such as commercial concentrates. Skipton Fund Application Form p3 SKIP000023\_107

941 The wording on the application form did not use that precise language. It asked the doctor to “*confirm that the patient has been chronically infected*” which meant infected for longer than six months. Counsel Presentation on Skipton Fund 22 March 2021 p9 INQY0000245

942 Signs are matters which can be clinically determined such as the results of a liver function test. Symptoms are subjectively experienced, such as tiredness, pain, stomach cramps, itchy skin, brain fog etc. However, “symptoms” seem to have been less important in the assessment a doctor had to make, since the form steered the doctor completing it more towards signs: “*If the applicant is PCR negative is there radiological or pathological evidence that they were chronically infected after the acute phase (ie the first six months) of the illness had passed? (Relevant radiological or pathological evidence would include chronic-phase raised liver-function tests, previous consideration for treatment, liver histology or radiography, other symptoms of chronic Hepatitis C.)*” Skipton Fund Application Form p9 SKIP000023\_107

943 Something, after all, had led the individual to make a claim. Such was the generally insidious nature of Hepatitis C infection at its start that it is difficult to think that a person suffering from it would have realised that they might have a claim on the Skipton Fund if they could recall no indication why they should. It may be that some, who had little idea that they had suffered anything untoward, had a blood test on some later occasion which showed antibody to Hepatitis C, whilst showing no active infection, but few of this class were likely to make a claim.

The evidence of Professor Howard Thomas<sup>944</sup> was that some 20-30% of the infected cohort cleared the virus naturally within three to six months of infection. Statistics suggested that only 1% did so after that.<sup>945</sup> Accordingly, if the evidence available to decide an application showed only that the applicant had once been infected, but no longer was, it is – viewed as a matter of statistics alone – more likely that the applicant was one of the 20-30% group than the 1%. It would be 20 to 30 times more likely that the individual never had a chronic infection. In the absence of some evidence of symptoms beyond the six month cut-off, no individual – even if belonging to the 1% – would hope to succeed.

There is a conceptual problem in taking this approach. The underlying assumption is that the 1% cohort typifies applicants to the Fund just as it typifies the generality of those who are infected with Hepatitis C. Yet this misses the fact that there is an important distinction: those who applied to the Fund would have to have had a reason to cause them to apply. The rest would not have had that reason. To be an applicant, there must have been something that sparked them into making that application. If they had suffered nothing remarkable in the way of symptoms, there would have been nothing to alert them to the possibility they may have had Hepatitis C, let alone that it was linked to a transfusion in their past.

Focussing upon the fact that the applicant thought, or had been told, that they might well be entitled to a payment from Skipton, why would they think this? Many would not have experienced symptoms within the first six months. Often the initial symptoms of Hepatitis C infection are unspecific, and might be caused by a number of common conditions – as a result, an individual could suffer all the symptoms of Hepatitis C, and never become aware of the fact that all their symptoms had a single, viral cause. So, usually, there would have been little to alert the individual to the possibility that they might have had Hepatitis C. Yet at some stage before making their application they must have been alerted to that possibility. By definition they would not have been tested for the virus after the six-month watershed between acute and chronic infection until they had a test which showed both signs that they had had an infection, and no sign it was still active. If they had been tested after the six-month watershed, and had proved then to have an active infection, it is plain that no question mark would hang over whether they were natural clearers or not. They would have suffered a chronic infection, even if it no longer remained active. They would be one of the small number of “late clearers”.

The chances are heavily against individual applicants learning there might be money to be had, thus arranging to be tested to see if they had ever suffered from the infection that

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944 A consultant hepatologist who was a director of the Skipton Fund from around late 2012 to 2018 and a trustee of the Caxton Foundation from 2011 to 2018.

945 Professor Howard Thomas Transcript 24 March 2021 pp18-19 INQY1000112. Different figures were given by others. Professor Christine Lee (though not a hepatologist, she had some experience with testing for non-A non B Hepatitis in people with haemophilia in 1983) suggested 15-20%. Letter from Professor Lee to William Connon 14 February 2005 DHSC0004520\_006. The guidance for applicants submitting an appeal used the range 15-30%. Skipton Fund Appeal Guidance p3 NHBT0090738. The evidence of the Expert Group on Hepatitis (therefore giving the authoritative view on the most up-to-date material) was that roughly 20% will clear spontaneously, depending on the dose and “*perhaps on other factors about the person themselves*”. (Professor John Dillon) Hepatitis Expert Panel Transcript 26 February 2020 p62 INQY1000052

triggered payment, and then managing to persuade their own clinician that it was likely to be the case that they had had symptoms which persisted for more than six months after a relevant transfusion. The “something that sparked the application” might indeed be the fact that they had been tested and realised that at some time previously they had been infected by Hepatitis C. This might be the consequence of seeking to donate blood, and then being told of the possibility of past infection. But otherwise a clinician would have had to arrange for such a test to be done and that clinician would have had some basis to suspect that Hepatitis C infection might be a possibility, even if only to seek to discount it as the explanation of some current problem: else why test for it, especially since such tests were not routine? A factor in a clinician’s decision to ask for such a test might well have been an applicant’s own retrospective realisation that they had suffered adverse effects after the six-month watershed, had wondered if these might be the result of some infection, and asked their doctor. In either case, there would have been some reason suggestive of continuing infection to seek the test.

Although applicants are thus necessarily to be distinguished from others who suffered Hepatitis C and had ceased to do so, by the simple fact that they were applicants, there was no space in the application for them to say what it was that had prompted them to apply.

The effect of the practice in respect of natural clearers was thus to exclude any prospect of payment to a whole group, even though it was known that a minority of that group would probably have suffered chronic infection. Evidence that might have helped the individual establish this (such as evidence of symptoms indicative of a continuing infection) might have made the difference. It would have had to be put into the balance against the percentage of natural clearers.

This introduced a difficulty for clinicians who had to certify answers to questions asked of them in Part 2 of the form of application.<sup>946</sup> The first question in Part 2 was (a) “*Has an HCV antibody test ever been positive?*” asking for a YES/NO answer.<sup>947</sup> It then asked: (b) “*Is the applicant currently PCR positive?*” again seeking a YES/NO answer.<sup>948</sup> If that was answered “YES” it would be clear that the applicant was eligible providing that they had incurred the infection through their treatment. It is the next two questions which combined with the first two created problems. Essentially, they asked whether the applicant tested negative as a result of past or ongoing interferon-based treatment, and whether there was evidence (radiological or pathological) that they were chronically infected after the first six months of the illness had passed.<sup>949</sup>

This had the potential to eliminate those who had cleared the virus from their system after more than six months, but had been left with devastating after-effects from it: one such

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946 Part 1 asked for the name and contact details of the applicant: nothing more than that.

947 Skipton Fund Application Form p9 SKIP0000023\_107

948 PCR stands for polymerase chain reaction. A positive test would indicate current infection.

949 A later version of the form asked doctors to provide a copy of medical records which confirmed their answers. Counsel Presentation on Skipton Fund 22 March 2021 p12 INQY0000245

example was someone whose eligibility for Stage 1 was in doubt but who qualified for Stage 2 since they had developed cirrhosis of the liver.<sup>950</sup>

The problem was taken up by Peter Stevens who had been charged with the responsibility of helping to get the Fund up and running. He became concerned about an inconsistency of approach within the Fund on this issue. One of the directors of the Fund, Elizabeth Boyd, who worked at the Royal Free as a welfare rights officer, had spoken there to Professor Christine Lee. Professor Lee apparently had told her that no one who was PCR negative but had not been treated would have raised liver function tests, evidence through liver histology or radiography, other symptoms of chronic Hepatitis C, or been previously considered for treatment.<sup>951</sup> Elizabeth Boyd was not, therefore “*passing any ‘natural clearers’*” whereas Peter Stevens as a director had passed “*quite a lot*” of “*natural clearers*” (ie those who had cleared the virus without receiving treatment, but had done so after the first six months had passed since the initial infection). The Fund directors had thus been adopting an inconsistent approach.

Peter Stevens proposed to Richard Gutowski that the distinction between those who cleared viral infection following treatment and others who cleared naturally should be abandoned.<sup>952</sup> He understood that the reason Professor Lee was not passing any spontaneous clearance applications to the Fund was that she believed “*the whole attempt to exclude them to be logically or scientifically flawed.*”<sup>953</sup> Other haemophilia centres took a different approach; some echoed the Royal Free’s position on it.<sup>954</sup>

A teleconference was arranged by the Department of Health to discuss the inconsistency in the reviewing of natural clearers by clinicians. It took place on 21 September 2004.<sup>955</sup> Professor Lee spoke about her concerns regarding inconsistency in the reviewing of natural clearers. Clear instructions were needed to eliminate the disparity. She recalled a case where one of her patients had taken 25 years to clear, with samples fluctuating between positive and negative throughout. She thought the patient was ineligible. However, the group disagreed: the individual must have cleared in the chronic phase and so was eligible. It was suggested that doctors who were now completing the forms were unlikely to have been treating the applicants at the time they were infected, and so would be unable to report accurately as to whether their patient had shown any signs or reported symptoms consistent with ongoing infection beyond six months – and then, as recorded in the notes

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950 Email from Peter Stevens to Richard Gutowski p3 DHSC5346927

951 Email from Peter Stevens to Richard Gutowski p3 DHSC5346927. The email refers to the application form: Skipton Fund Application Form p9 SKIP0000023\_107

952 Email from Peter Stevens to Richard Gutowski p3 DHSC5346927

953 Email from Peter Stevens to Dr Mark Winter 8 September 2004 HCDO0000242\_102. Professor Lee was asked about this when compiling her written evidence to the Inquiry but did not recall it, though she did not then have a copy of the note of the teleconference described next in the text to prompt any recollection. Written Statement of Professor Christine Lee para 149 WITN0644058

954 Email from Peter Stevens to Richard Gutowski and others 19 November 2004 p1 DHSC5352926

955 Minutes of Skipton Fund Teleconference meeting 21 September 2004 DHSC0004510\_080



of the meeting, that “*asking the patient is not viable given the £20,000 at stake.*”<sup>956</sup> This is open to the criticism that it assumed patients would not be straightforward. Further, it does not seem to have been suggested that appropriate questions might have helped provide answers from the applicant, which would help a decision-maker to determine the issue. This was a missed opportunity to improve the quality of information given by the forms.

However, the overall message from the meeting appears clear from the record. It emphasised that acute stage clearers were not eligible<sup>957</sup> whereas chronic stage clearers were eligible. It was decided to reiterate to Professor Lee that patients who cleared in the chronic phase **were** eligible for payment.<sup>958</sup>

This might be thought to have sorted the problem. However, when Richard Gutowski emailed Peter Stevens to explain the conclusions that had been reached he said “*As far as spontaneous clearers are concerned ... our position remains unchanged. They do not come within the scope of the Scheme.*”<sup>959</sup> This was inaccurate, since it did not reflect the distinction, clear to a reader of the note of the meeting, which was to be made between those who had cleared viral infection during the acute phase (the first six months) and those who had cleared later, as stated on the application form.<sup>960</sup>

An email exchange followed. Peter Stevens responded to Richard Gutowski that there were about 80 applications in which the answer to the fourth question on the application form (“*Was there evidence that they had been chronically infected after the acute phase had passed?*”) had been yes and that unless Professor Lee advised her fellow directors differently that they would “*presumably have to fail the lot.*”<sup>961</sup>

There followed further correspondence between Richard Gutowski and Peter Stevens in which the former said at one stage “*Ministers have made their decision*”<sup>962</sup> and Peter Stevens pointed out that a number of centres considered that the distinction between spontaneous clearers and others was ill-founded and so would not “*attest*” to the evidence the Department

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956 Minutes of Skipton Fund Teleconference meeting 21 September 2004 p1 DHSC0004510\_080. It is not clear from the note whether this is the group’s collective view, or the personal views of Professor Lee, whose contribution to the meeting was being discussed in this part of the note.

957 It appears to have linked eligibility with physiological damage and assumed there had been no such damage from infection cleared in the first six months. See footnote 917.

958 Minutes of Skipton Fund Teleconference meeting 21 September 2004 p2 DHSC0004510\_080

959 Email chain between Richard Gutowski, Peter Stevens and others 4 October 2004 p3 DHSC0004520\_059

960 Skipton Fund Application Form p3 SKIP0000023\_107

961 Email chain between Richard Gutowski, Peter Stevens and others 4 October 2004 p2 DHSC0004520\_059

962 Email chain between Richard Gutowski, Peter Stevens and others 8 November 2004 p2 DHSC0004520\_056

of Health required.<sup>963</sup> This episode<sup>964</sup> ended when Peter Stevens was able to write to Dr Mark Winter that “*Gutowski was leaping up and down and telling us to pay the natural clearers with chronic stage infection evidence at once ... I am about to call Gutowski to say that we will do what we’re told ... So your discussions [at the United Kingdom Haemophilia Centre Doctors’ Organisation] might need to focus on what to do about those left out.*”<sup>965</sup>

The Agency Agreement under which the Skipton Fund operated was not finalised until the first version of it was signed on 22 May 2007. This defined the position in respect of “natural clearers” in these terms: “*People who acquired hepatitis C but spontaneously cleared the virus in the acute stage and did not develop chronic hepatitis C infection are not eligible for payments under this scheme.*”<sup>966</sup> Since it also defined people as eligible if they “*became infected with the hepatitis C virus, and developed chronic infection*” the dividing line is clear. The problem remained a factual one: had the individual applicant continued to suffer infection for more than six months after the causative treatment?

This account reveals three problems. First, the uncertainties around natural clearers were such at the start of the Fund’s operations that a number of applicants were not put forward by their doctors, but would qualify under the rule as clarified. There is no record of any orchestrated attempt to invite them to re-apply; the opportunity will almost certainly have been lost for good. Second, although in the main those who cleared Hepatitis C would statistically be likely to do so within the first six months there was no opportunity for a person to explain why they considered that they had continued to suffer Hepatitis C infection

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963 Email chain between Richard Gutowski, Peter Stevens and others 8 November 2004 p1 DHSC0004520\_056. Richard Gutowski’s colleague had clarified that “*It should be assumed that the virus has been cleared in the acute phase unless robust medical evidence is cited that proves, on the balance of probabilities, that the patient experienced chronic infection i.e. infection that extended after the first six months of illness.*” Email chain between Richard Gutowski, Peter Stevens and others 8 November 2004 p4 DHSC0004520\_056

964 After this, there was still some correspondence about the natural clearer issue. Representations were made by the United Kingdom Haemophilia Centre Doctors’ Organisation (“UKHCDO”) and the Haemophilia Society (see Minutes of Directors of The Skipton Fund meeting 25 April 2005 p1 SKIP0000030\_035) which resulted in a response from the Department of Health (Letter from William Connon to Graham Whitehead 7 July 2005 p2 HSOC0009251) making the Government position clear that where people cleared the virus spontaneously after a period of chronic infection they were eligible, although this was not thought to be a common occurrence.

965 Peter Stevens was continuing to advocate expanding the Fund to include people who had cleared in the acute phase. Email from Peter Stevens to Dr Winter 26 November 2004 p2 HCDO0000242\_054. It should also be noted that Professor Lee wrote (to William Connon who took over responsibility for blood policy from Richard Gutowski) to say that “*the fairest thing would be that any individual who was infected with hepatitis C should receive payment.*” Her argument appears to be that “*due to the inexperience in the field of hepatitis C of many of my medical colleagues*” some people had received payment “*although in actual fact they are natural clearers*”, but that “*most people with haemophilia acquired hepatitis C infection in the late 1970s*” and “*They clearly had had a lot of worry about the implications before we were able to assure them that they had cleared the virus naturally.*” Letter from Professor Lee to William Connon 14 February 2005 DHSC0004520\_006. This is focussed on people with haemophilia and the Fund of course had a wider number of people who did not have haemophilia but had had transfusions. Professor Lee was here recognising that there could be significant psychological consequences of infection, whenever cleared. Contrast the position articulated by Bob Stock and Ailsa Wight as recorded in footnote 917.

966 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 p23 SKIP0000033\_066

beyond six months, nor could the Fund examine their evidence on the point.<sup>967</sup> This feature was a function of the design of the Fund, and the way in which the Department of Health set out to operate it.<sup>968</sup> It represents a significant drawback. Third, attention was drawn during the to-and-fro about natural clearers to cases in which psychological or psychiatric damage had resulted, though no physiological damage may have accompanied it. One example was a case (“S”) of one of the claimants in *A and Others v the National Blood Authority*, in which a 17 year old who was infected at age 7 had been awarded compensation by the court for an adjustment disorder;<sup>969</sup> and Professor Lee had recorded her concerns from her experience of her own patients about the psychological effects of the uncertainty of their knowing whether they had, or had not, cleared the virus before tests became available to show that they had.<sup>970</sup> Thus long-lasting effects, and their consequences, will have been suffered by some, but were left unrecognised by the Fund in its final form.<sup>971</sup>

## Second issue: the cause of the infection

A more difficult question than whether an applicant had been infected was knowing, and then being able to prove, the cause of the infection. Since, first, the **onset** of infection was typically not marked by any symptoms indistinguishable from a short-term cold or bout of flu, or repeated tiredness, before the range of symptoms became increasingly serious and concerning, and requiring of immediate attention, and, second, the transfusion (if that were the cause) typically was given some 20 years or more before it might lead to cirrhosis, it might well be that a sufferer would not necessarily link the two. Records which identified a particular blood transfusion were rare; and even the fact of having had a blood transfusion would often go unrecorded in such records as survive.

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967 Guidance on assessing an application for the £20,000 payment SKIP0000030\_045 sets out the guidance given to staff determining applications: “*Evidence is defined as –*

- *information supplied on an application form;*
- *authentic documentation (eg. from any NHS establishment, the National Blood Service etc);*
- *opinion, confirmation or signed authority from a practising clinician; or*
- *attestation by an authorising signatory that the claimant has no history of intravenous drug misuse.”*

Since the application form itself asks the applicant to fill in only their identifying details, and leaves no space for anything more, it follows that the guidance would not regard any accompanying letter or further comment as “*Evidence*”. If therefore a person had good reason personally to recollect that they had been given a transfusion, or had been told by a clinician that this had happened, their saying or writing this had no effect. The best they could hope for would be that the clinician concerned would quote it sympathetically, though some might consider they could not sign to verify a transfusion which they thought probably had occurred when they felt that they did not actually know it had.

968 The application form was agreed by the health departments in the four nations. Letter from Peter Stevens to Roddy Morrison 2 April 2004 HSOC0016834, Email from Bob Stock to David Reay and others 10 May 2004 SCGV0000258\_072

969 The disorder had lasted 3.5 years. Reference to it is made in both the judgment in the case and in the report of the working party chaired by Matt Kelly QC to which Dr Giangrande drew attention in his letter of 24 October 2003, referred to above. *A and Others v National Blood Authority* Judgment 26 March 2001 para 234 PRSE0003333, Report of the Hepatitis C Working Party June 2002 p28 HSOC0005927, Letter from Dr Giangrande to Dr Nicholas 24 October 2003 DHSC0004421\_005

970 Letter from Professor Lee to William Connon 14 February 2005 DHSC0004520\_006

971 For the Inquiry’s recommendations about the parameters of natural clearers, see the Inquiry’s Report on Compensation. Infected Blood Inquiry Second Interim Report 5 April 2023 pp39-40 INQY0000453

As can be seen from the figures quoted above, the majority of applications were accepted. However, what is troubling is that out of those who appealed after refusal by the administration (“the Office”) very nearly half (49.6%) succeeded.<sup>972</sup> This suggests that refusals were correctly made only half of the time. It indicates serious flaws in the way in which the system operated. There are three possible reasons for this: that the Appeals Panel was more generous than perhaps it should have been; that the decision maker first time round was misapplying the tests; or that information was available on appeal which was not considered first time round. The Inquiry had the advantage of hearing both from Nicholas Fish, who was responsible for the first line decision, and Mark Mildred who chaired the Appeals Panel throughout. Their evidence leads to the conclusion that it is likely to have been a combination of the second and third factors mentioned above.

Nicholas Fish is not personally to be criticised for this. He began working for the Skipton Fund in November 2004 as a temp. He was the assistant to the then administrator, helping to write letters, gather evidence, answer emails and carry out general administrative duties.<sup>973</sup> When the first administrator was found to be defrauding the fund in 2006, the need for some continuity meant that Nicholas Fish succeeded to the job. The systems he operated were those he inherited, and had experience of applying.<sup>974</sup> For him, it was largely a case of conducting business as before.<sup>975</sup> He did not ask many searching questions about whether the process he adopted was correct, nor how appropriate his decision-making was, largely because he understood, generally, that these were what the Department of Health expected of someone in a position such as his. The Skipton Fund was an agent of the Department, and was expressly forbidden in the Agency Agreement to raise matters of policy with the Department. It was left to his judgement whether or not to discuss any given case with a director. In those circumstances, he did as had previously been done.<sup>976</sup>

The application form required the clinician who was completing most of it to specify any records which substantiated the transfusion upon which the claim was based, to provide a “YES/NO” answer to the question “*If the date of infection cannot be proved, do you believe infection occurred before 1 September 1991?*”, and it finished with the “roll-up” question: “*In your view is it probable that the infected person’s HCV infection was acquired in consequence of NHS treatment received before 1 September 1991?*”<sup>977</sup>

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972 220 out of 443 appeals approved. Counsel Presentation on Skipton Fund 22 March 2021 p18 INQY0000245

973 Written Statement of Nicholas Fish paras 3.1-4.1 WITN4466002

974 Written Statement of Nicholas Fish para 13.1 WITN4466002

975 Nicholas Fish Transcript 23 March 2021 p6 INQY1000111

976 A revealing example of the way in which he exercised his functions relates to natural clearers. If there were difficulty in his deciding an application on its merits, he would refer to a director, Elizabeth Boyd, who had contacts with the Royal Free Hospital. She might then discuss it with a doctor or doctors there, and revert to Nicholas Fish. To him, “*it seemed to be working well. The opinions seemed to be sound.*” When asked how he judged that the opinions were sound he responded: “*Well, I trust the judgement of a clinician, so I had no reason to think they wouldn’t be sound*”, which he accepted amounted to assuming they were. He added “*I didn’t ever think anything sounded unusual*”, which again begs the question whether someone with little personal medical experience or expertise would be able to judge this with any certainty. Nicholas Fish Transcript 23 March 2021 pp11-14 INQY1000111

977 Skipton Fund Application Form p11, p13 SKIP0000023\_107

For both people with haemophilia and others what was required was proof – on the balance of probabilities – that NHS treatment was the cause of infection by Hepatitis C. In the case of an applicant with haemophilia, the assumption could more easily be made that the most likely cause of hepatitis was the receipt of coagulation replacement therapy by blood product. For other people however, the way in which causation had to be proved in practice was flawed. The test was that the applicant’s doctor not only had to say that they had seen records but, in the aftermath of Keith Foster’s fraud being uncovered, they were also expected to provide a copy of the relevant parts of the records, if they existed.

There were three problems with taking this approach. First, records were not always available or had been lost or destroyed. In a number of cases, the hospital where the treatment was said to have been administered no longer operated, and the records were unlikely to be traceable if they ever existed. Second, where GP records for the time were available, they may have included discharge letters which may have referred to transfusions, but equally may not.<sup>978</sup> Third, an applicant would be unlikely to know about and apply to the Fund unless they believed that they had had a transfusion.<sup>979</sup> Yet there was no place on the application form for applicants to set out the reasons why they thought this was the case – for instance, what they had themselves experienced, or friends or family might have reported to them and might be able to substantiate, or from what they recollected a nurse or doctor had said to them at some stage during their treatment.<sup>980</sup> Further, the guidelines for staff assessing applications did not permit them even to consider it as evidence, though it plainly would be taken into account in any legal context.

A standard of proof on the balance of probabilities is a deceptively simple test. Is the event more likely to have happened than not? That is to be determined by the evidence. What a witness has to say is evidence: it may often be overlooked that a person who is witness to

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978 During the testimony of witnesses about blood transfusion services (Professor Dame Marcela Contreras, Dr Patricia Hewitt and others) it became clear that though records should have been made to show that a transfusion had been given, and identifying numbers of the transfused units recorded, practice about this was often casual, and in addition records if indeed made in the first place were often not retained for the length of time necessary to help show some years later that a transfusion had taken place. Professor Dame Marcela Contreras Transcript 2 December 2021 p116 INQY1000165, Dr Patricia Hewitt Transcript 9 December 2021 pp178-182 INQY1000170

979 Though it may theoretically be the case that a person with active Hepatitis C infection claimed to have had a transfusion in order to benefit, there is no concrete evidence that this occurred, and it seems unlikely given the need for the clinician treating that person to accept that their account was probably accurate, even if not reflected clearly in the medical records available.

980 It was not even regarded as evidence under the guidance for the initial assessment. As already noted, the guidance on assessing an application for the £20,000 payment said: “*Evidence is defined as –*

- *information supplied on an application form;*
- *authentic documentation (eg. from any NHS establishment, the National Blood Service etc);*
- *opinion, confirmation or signed authority from a practising clinician; or*
- *attestation by an authorising signatory that the claimant has no history of intravenous drug misuse.”*

Guidance on assessing an application for the £20,000 payment p1 SKIP0000030\_045. None of this allows for the first-hand evidence of the applicant that they had had a transfusion, since it was not part of the information to be supplied on the application form used. By contrast, not only first-hand evidence but also hearsay evidence (what someone has said to the witness giving evidence) is admitted in the courts as evidence of the facts stated in it. This is subject to safeguards, depending on the context, which it is unnecessary to go into here, but it is certainly now commonplace and was at the time the guidelines were formulated.

their own treatment is therefore capable of giving evidence about it themselves. They are a witness, even if not independent. Unless their evidence is not capable of holding belief (for example, it is inherently improbable, there are particular reasons for not believing it or the witness giving the account, or there is evidence to the contrary which on balance is stronger) that evidence is sufficient to satisfy the standard of proof. The recollection of someone who was there, who recalls at the time having understood for good reason that they had a transfusion, is likely in most cases to outweigh the fact that the available records do not mention any such transfusion as having taken place.

The eventual decision is to be reached not by taking a view as to whether the approach should be permissive or restrictive, but strictly by reference to whatever evidence there is. If there is, truly, **no** evidence that there was a transfusion then the burden of proof cannot be satisfied. A “50-50 situation” does not tip the balance of probability in favour of a transfusion being the cause. If, however, there is **some** evidence, then it becomes a question of whether there is any evidence to counter it, and if so how strong that is. It cannot be assumed that applicants are telling untruths because they stand to benefit.<sup>981</sup> Indeed, they will all have satisfied the criterion of showing that they have a diagnosis of Hepatitis C. It came from some cause. What they had to show was simply<sup>982</sup> that a transfusion was more likely to be the cause than any other factor.<sup>983</sup>

Skipton operated two policies in practice: the first that, in general, in the absence of medical records showing either expressly or by necessary implication that there had been a transfusion at a time which might conceivably give rise to symptoms when they first emerged, a claim would be rejected by the office. The approach of seeking medical records to substantiate a transfusion assumed that there should be such records in existence. This was a wholly unrealistic assumption. Some could be found; some could not. Some had been lost or destroyed through no fault of the applicant. It also assumed that the record would show whether there had been a transfusion or not. This, too, was an assumption of perfection, whereas the truth was known by at least some in the Department of Health to be different.<sup>984</sup> Some records did, but some did not. In the absence of any NHS transfusion records, reliance might have been placed on a discharge letter to a doctor. It could not, however, be assumed that such a letter would refer to a transfusion. It was unrealistic to suppose that every detail of treatment would be recorded in such a letter. This also assumes that a letter sent to a GP, as discharge letters were, without a copy being sent to the patient in those days, would necessarily find its way into the medical notes. This did not always happen.

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981 Again, there may be said to be a contrast with court proceedings. In most civil cases, the claimant will be seeking an award of damages: that does not mean that their evidence is automatically to be assumed to be untruthful.

982 It is the question which is simple to express: its resolution may be a little more complex than that.

983 Or other possible causes, put together.

984 At a meeting attended by Richard Gutowski and Bob Stock on 30 July 2003 there is evidence that they did know: “*it is envisaged that claimants will generally be given the benefit of the doubt (eg. because of lost/destroyed medical records etc).*” Notes of Scottish Executive and Department of Health meeting 30 July 2003 p2 DHSC0004421\_141

In short, the combination of placing reliance on the existence of records of a transfusion, whilst in practice excluding (and not requesting) whatever evidence the applicant could offer to show that one had been given, was indefensible: a person infected by a failure of treatment from the state was now faced additionally with a failure of record keeping by the state, which led to a failure of their claim because of the inadequacy of the system set up by the state.

The second policy which operated was to regard some material as excluding a claim altogether, without exception. There were two main examples of this. One was where it was apparent that the applicant had used recreational drugs in the past. Where this involved intravenous drug use the claim was rejected almost as a matter of course. However, some applicants who admitted to intranasal or oral drug consumption, but not to injection, were also denied on the basis of intravenous drug use, even though their medical records contained no reference to any such use.<sup>985</sup>

The second example of note was where the claim was for hepatitis caused by the administration of anti-D. This too was likely to be rejected unless there was also evidence of blood transfusion.<sup>986</sup>

These two exclusions, applied as though they were absolute bars to a claim, relied upon the way in which two expert reports were interpreted: respectively the Ramsay Report in respect of intravenous drug use, and two letters of advice from Dr Patricia Hewitt of National Blood Transfusion Service in respect of anti-D.

As to the former, Dr Mary Ramsay of the Health Protection Agency Centre for Infections was asked for advice by Nicholas Fish, acting as secretary to the appeals panel, on the extent to which science and statistics showed that injecting drug use for less than two years was likely to be a cause of an Hepatitis C infection, where the sufferer also had a history of blood transfusion. She reported on 19 March 2007. Her conclusion was that:

*“Overall, the risk of hepatitis C infection with short term injecting in the UK is poorly documented, and is likely to have varied geographically and over time. Although data on one-off or casual injectors is absent, evidence from many countries supports the belief that the risk of acquiring hepatitis C in the early period of injecting is high. The estimated probability of transmission from single*

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985 See Counsel Presentation on Skipton Fund 22 March 2021 pp55-58 INQY0000245. Evidence of this also comes from the Skipton refusal files viewed by the Inquiry. There is material which shows that a balance has to be struck: the professional experience of Professor Thomas led him to think that a “well validated history of intravenous drug use” meant “you could virtually be certain that that was the cause of their hepatitis”, and in his experience patients who would not admit to using drugs at a first consultation might, for instance, “after four or five returns and follow-up clinics ... say ‘Well, actually, as a student once I did use them.’” Professor Howard Thomas Transcript 24 March 2021 pp70-71 INQY1000112. Striking the appropriate balance plainly requires a close examination of the circumstances, which in most cases should – but did not – involve the panel hearing directly from the applicant and making the appropriate, if difficult, assessment: this was not the fault of the Appeals Panel, for it was not permitted to hold oral hearings. It was a serious flaw in the design of the scheme.

986 Although there has been a case in which a claim that anti-D was a cause of hepatitis was accepted, this appears to be exceptional. As a general rule, it was not accepted that anti-D injections prepared by the NHS and administered intramuscularly could give rise to hepatitis.

*episodes of needle and syringe sharing also appears to be substantially higher than the risks associated with a single transfusion of unscreened blood. On an individual basis, it will be difficult to assess the risks associated with single episodes of injecting where sharing is denied, but recent studies suggest that the incidence of hepatitis C in injectors who deny sharing is around half of that observed in those that do report such behaviour.”<sup>987</sup>*

This material gives pause for thought. Although it is clear that studies suggest that having ever injected drugs is a risk factor for Hepatitis C, a simplistic conclusion that any drug use would always be the more probable cause of an infection than a transfusion overlooks the qualifications in her summary and would inevitably be unfair to some applicants.<sup>988</sup> Intravenous drug use rightly had to be factored in to any assessment of probability. But fairness also places central importance upon the assessment of the quality of recollection of the individual concerned. It is difficult to see how such an assessment could be done fairly on paper (for instance, where an applicant insisted that they had always used a fresh needle, or had injected on one occasion only, well before the very first symptoms of hepatitis were apparent) if the likely conclusion from the application as it stood on paper was that the account should be rejected. Rather, fairness would call for a short hearing during which the individual would be invited to give an account, and the panel would assess its reliability. Unfortunately, at no stage during the Skipton Fund procedures (either when the application was first considered by the Office, or secondly, if appealed, on appeal) was there any room for an account to be given personally.<sup>989</sup>

As to anti-D, Dr Hewitt wrote to Keith Foster on 24 February 2005. She said that anti-D immunoglobulin produced within the UK *“has been used over many years and has an unparalleled safety record with regard to transmission of viruses. There are no established reports of infection transmission by the intramuscular product produced within the UK since treatment began.”* She went on to note, on the other hand, that there had been well-documented transmission episodes from anti-D produced outside the UK. The most well known of these involved anti-D prepared by the Irish Blood Transfusion Board during the 1970s and early 1980s. It had transmitted Hepatitis C to a large number of women treated with anti-D after childbirth. She commented that they involved a *“completely different method of manufacture from that used within the UK”* and that they were intravenous preparations. Since some Irish anti-D had been imported into the UK and used on a named patient basis on a small number of women, she added *“There may be a few women who received product manufactured outside the UK, which might have presented a risk of hepatitis C infection. In*

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987 Report on Response to the letter from the Skipton Fund 19 March 2007 p4 SKIP0000031\_217

988 Presumably a “single” transfusion is of one unit of blood. If more than one unit were given at the start of a timescale consistent with it being the cause of the later development of Hepatitis C that might be thought to increase the degree of risk.

989 The appeal procedure was expressly a determination on paper alone. The scheme excluded hearing orally from an applicant. Mark Mildred noted in relation to intravenous drug use: *“More extensive disclosure and oral evidence tested by cross-examination might have given a more detailed picture and a better informed basis for the assessment of credibility but these were not open to us.”* Written Statement of Mark Mildred para 50 WITN5258001



*order to totally exclude this scenario, it would be necessary to know whether there are any reasons to believe that non-UK product was used. This would only have been in exceptional circumstances and not for routine treatment during and after pregnancy.*<sup>990</sup>

On 15 July 2010, Dr Hewitt wrote again to Nicholas Fish. She reported that prior to universal Hepatitis C screening of blood and plasma donations being introduced (ie prior to September 1991, the cut-off date for claims to the Skipton Fund) *“more than one half of the intramuscular preparations of immunoglobulins contained detectable HCV RNA.”* Despite that, she said that transmission of the virus had not been documented as having arisen from the intramuscular preparation prepared according to the Cohn fractionation process used in UK manufacture. This was different from the manufacturing process for intravenous immunoglobulin. She went on to describe *“an unfortunate experience”*. This was the arrangement by the Blood Products Laboratory (“BPL”) of a comparative study of intramuscular immunoglobulin and intravenous intramuscular immunoglobulins. Both had been manufactured by BPL. All 12 patients who received the intravenous preparation had previously received intramuscular therapy without apparent ill effect. Nevertheless, all 12 developed non-A non-B Hepatitis soon after starting the intravenous treatment. None of those receiving intravenous muscular product did so. The consequence was that BPL thereafter ceased making intravenous immunoglobulin preparations.<sup>991</sup> There may have been some occasions when IV preparations prepared in Ireland (which were risky, just as the BPL product had been) were given, but these appear on available material to have been few in number.

Neither the Ramsay Report nor either of the two letters from Dr Hewitt were offered to applicants whose applications were rejected on the basis of their contents. They were thus ignorant of the detail of the reasoning that had led to the rejection of their claims, and unable to challenge that reasoning. Nicholas Fish told the Inquiry that if they had asked for copies of the letters and reports, they would have been provided.<sup>992</sup> It remains unclear why the onus was placed on a disappointed applicant, who was by definition suffering from the effects of Hepatitis C,<sup>993</sup> to ask for copies rather than on the Fund to provide them in the first place.

## Stage 2 payments

Someone who already qualified for a Stage 1 payment met an essential requirement for one under Stage 2. They had shown that they probably suffered chronic Hepatitis C as the result of relevant NHS treatment. The Agency Agreement said that a Stage 2 payment would be made to such a qualifying person who had *“an advanced stage of illness due to hepatitis C virus because of receiving blood, blood products or tissues from the NHS prior to September 1991.”* What precisely amounted to *“an advanced stage of illness”*? It was said: *“In this*

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990 Letter from Dr Hewitt to Keith Foster 24 February 2005 p2 SKIP0000031\_071

991 Letter from Dr Hewitt and Dr Clive Dash to Nicholas Fish 15 July 2010 SKIP0000031\_070

992 Nicholas Fish Transcript 23 March 2021 pp67-68, pp73-74 INQY1000111

993 Including for example brain fog.

*context, persons with cirrhosis or primary liver cancer and those who have received, or are on the waiting list to receive, a liver transplant are eligible to apply for a stage 2 payment.*<sup>994</sup>

These categories were the result of advice from an advisory group on hepatitis which reported in 2003 to the Department of Health. Professor Thomas was one of the members. The note of the meeting recorded that *“the experts were asked for their initial thoughts on the medical trigger for the second (higher) payment. It was felt that this should be a recognised stage of the disease, rather than subjective symptoms of illness.”*<sup>995</sup> In his oral evidence to the Inquiry Professor Thomas said *“we were looking for objectivity, really, something that would allow whoever to implement this with a solid break-point, really, when you move from stage 1 to stage 2.”*<sup>996</sup> It was also felt that there would be something of a marked change once cirrhosis developed. This understanding was slowly overtaken by developments in medical knowledge. He said that realisation dawned on two matters: first, that a number of those without cirrhosis developed depression and brain fog, and, second, that the trigger point should not be left too late, because, once cirrhosis began, there would be an enhanced risk of liver cancer even if the underlying infection were then cleared.<sup>997</sup>

As a consequence of these improvements in understanding the nature of the progression of the disease, what had seemed like a logical bright line rule was no longer so justifiable. It could now be seen as ruling out claims from those who were symptomatic, but who did not yet have cirrhosis. In not distinguishing between the symptomatic and the asymptomatic it seemed to have become unfair. Moreover, those whose infection had been diagnosed but who were pre-cirrhotic often underwent treatment. Until the 2010s, this usually involved interferon, often pegylated<sup>998</sup> and more often than not this was coupled with ribavirin. There is no doubt that this treatment gave rise to serious, often close to horrific, side-effects in most cases. Yet it was often ineffective.<sup>999</sup> Usually the treatment had an immediate negative impact, and often gave rise to persisting problems. These were not merely physical, since there was also the psychological impact of having undergone a lengthy period of treatment<sup>1000</sup> suffering very difficult side-effects, seeing its effect on partners, family, close

994 Agency Agreement between Secretary of State for Health and Skipton Fund Limited 22 May 2007 pp5-6 SKIP0000033\_066

995 Minutes of Blood and Healthcare Associated Infections Unit meeting 14 October 2003 p1 SCGV0000265\_004

996 Professor Howard Thomas Transcript 24 March 2021 p7 INQY1000112

997 Professor Howard Thomas Transcript 24 March 2021 pp8-9, p19 INQY1000112

998 Attached to polyethylene glycol (“PEG”), due to its reported “stealth” properties and biocompatibility. It is generally thought that PEGylation allows particulate delivery systems and biomaterials to evade the immune system and thereby prolong circulation lifetimes.

999 See Figure 15.13b in the Expert Report to the Infected Blood Inquiry: Hepatitis. Effectiveness depended on the genotype. In the UK roughly 40% of infections are genotype 1; and 40% genotype 3. Between 1991 and 1999 when interferon alone tended to be the treatment, 7% of those with genotype 1 showed a sustained virological response (probable clearance) after a 48-week course of treatment; and 29% of those with genotypes 2 or 3. When ribavirin was added, between 1999 and 2002, these unhappy figures improved, but only to 28% and 66% respectively for a 48-week course; when pegylated interferon was used in combination with ribavirin (2002-2011) genotype 1 was still just 57% likely to be cleared; genotype 2 though was 83%, again after a 48-week course. Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p5, p43 EXPG0000001

1000 Regular injections over a 48-week period for the greatest chance of clearance – 24 weeks to have a lesser chance, to the extent that when interferon was used on its own only 2% of those with

friends and work, only to learn it had all been futile. Though the disease itself might not yet have resulted in significant fibrosis, for anyone treated who had the persisting after-effects of treatment with interferon, or interferon and ribavirin, highly unpleasant and sometimes devastating symptoms remained. The reasons for thinking that a clear line could be drawn between Stage 1 and Stage 2 in terms of symptoms and effects on life could no longer be maintained. It was far more a matter of degree. The Agency Agreement was slow to reflect these developments, by recognising that a distinction should be drawn between the levels of payment for those who were comparatively asymptomatic, or whose symptoms were limited, and those who, though not (or not yet) cirrhotic, had significant symptoms. It was amended in 2012, though the amendment was relatively limited: the definition of when a Stage 2 payment should be given now included the infected person developing B-cell non-Hodgkin's Lymphoma where that had arisen after the person contracted Hepatitis C.<sup>1001</sup>

The Archer Inquiry report<sup>1002</sup> led to a significant uprating of the payments to be made. The Secretary of State announced in January 2010 that:

*“Under new arrangements that we will introduce, this second stage payment will increase from £25,000 to £50,000 ... In addition, we will also introduce a new, annual payment of £12,800 for those with hepatitis C who reach this second stage. This is the same amount as those who were infected with HIV receive. Those infected with both HIV and hepatitis C from contaminated blood will now receive two annual payments of £12,800 if they meet the stage 2 criteria – one payment for each infection – along with the respective lump sums. All annual payments that are made, both to those so infected with HIV and to those with hepatitis C, will now be uprated annually in line with the consumer prices index to keep pace with living costs.”*<sup>1003</sup>

He also announced that a posthumous claim of up to £70,000 could be made on behalf of those infected with Hepatitis C who died before 29 August 2003. Previously, they had been excluded from the scheme.

Thus far, the Fund as it operated in each of the four nations of the UK was essentially the same. However, a further amendment followed in 2016.<sup>1004</sup> This now made specific clauses applicable to each nation. Scotland now decided to provide a top-up payment of £30,000 for those at Stage 1. To qualify for this a person had to have been alive from 1 April 2016 and not be “eligible for a Stage 2 payment of any sort”. Scotland also provided for a Stage 2 payment

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genotype 1 had a sustained virological response (a 98% failure rate).

1001 Agency and Services Agreement between the Secretary of State for Health and The Skipton Fund Limited 24 March 2011 (incorporating amendments agreed between the parties on 30 April 2012) p6 SKIP0000033\_062

1002 Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products by the Rt Hon Lord Archer of Sandwell 23 February 2009 ARCH0000001

1003 Statement on Hepatitis C and HIV-infected blood by the Secretary of State for Health 10 January 2011 pp1-2 DHSC5205794

1004 These changes followed a damning All-Party Parliamentary Group Report. Inquiry into the current support for those affected by the contaminated blood scandal in the UK January 2015 RLIT0000031

of £50,000 to be made to a person co-infected with HIV if they had not already received a Stage 2 payment.<sup>1005</sup> England and Wales provided a bereavement payment of £10,000 if a contributory factor to the person's death was Hepatitis C (or HIV if co-infected).<sup>1006</sup>

Annual payments were extended to people who had received Stage 1 payments as well as Stage 2.<sup>1007</sup>

The difference in payment levels between nations meant that it became more important to identify the nation responsible for the payment. The relevant country for the purposes of determining which payment a claimant was entitled to was, in summary, the country in which the claimant was treated (ie with the blood or blood product which was causative of the infection), with the proviso that where there was insufficient evidence to identify which country that was, it was the country in which the claimant first presented for treatment.<sup>1008</sup>

Apart from Scotland, therefore, none of the jurisdictions tangibly recognised the developing understanding of the severity of the symptoms suffered by those who had not yet developed cirrhosis. Their livers may have been slowly beginning to decompensate, but no additional payment was forthcoming.<sup>1009</sup>

It was also recognised only slowly that for those who were not, or not yet experiencing cirrhosis, the single payment was insufficient support. What was, in effect, a third category was necessary, a special appeal mechanism, which became known as the Special Category Mechanism. This was not, however, introduced during the time when the Skipton Fund operated.<sup>1010</sup>

### *Eligibility for a Stage 2 payment*

Eligibility generally required the establishment of criteria which were objective rather than subjective. This was seen as a clinical question. To establish that there was indeed cirrhosis, rather than there being increasing fibrosis of the liver which had not (yet) reached the level of cirrhosis, might most accurately be assessed by a biopsy. However, biopsy procedures are invasive, may often be painful, and take time to arrange: the results cannot be as quickly

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1005 Agency and Services Agreement between the Secretary of State for Health and The Skipton Fund Limited (as amended 11 November 2016) p31, p33 SKIP0000033\_057

1006 Agency and Services Agreement between the Secretary of State for Health and The Skipton Fund Limited (as amended 11 November 2016) pp27-28, pp38-39 SKIP0000033\_057

1007 Ministerial statement by Jane Ellison 14 July 2016 p1 CELC0000004\_021

1008 Agency and Services Agreement between the Secretary of State for Health and The Skipton Fund Limited (as amended 11 November 2016) pp20-21 SKIP0000033\_057. There are detailed provisions for each of the possibilities: infection by another person, bereavement, dependency and service in the armed forces.

1009 The Caxton Foundation however was established in 2011 as a discretionary charitable trust to support those entitled to be Skipton beneficiaries, and in addition to support their partners, parents, children and dependants. Thus viewed overall, there was a possibility that the schemes might provide some response to those whose symptoms were worse than those of others, but it was a very limited possibility: the Caxton Foundation lacked the resources to provide support for someone unable to work due to treatment or the consequences of treatment. See the chapter on the *Caxton Foundation*.

1010 Counsel Presentation on Skipton Fund 22 March 2021 p8 INQY0000245. See the chapter on *National Support Schemes*.

determined as those of other more readily funded and quickly available tests. Professor Thomas told the Inquiry that (absent biopsy) the ideal way of determining whether the Stage 2 threshold had been achieved was to use data already collected for the patient's care.<sup>1011</sup> This enabled the determination of the patient's Aspartate Aminotransferase to Platelet Ratio Index ("APRI") score. This score is determined by the relative levels of Aspartate Aminotransferase ("AST") in the blood (as the liver deteriorates, more AST, which is a protein, is discharged into the bloodstream and so levels of AST increase measurably). At the same time, where cirrhosis is present, the number of platelets in the bloodstream<sup>1012</sup> decreases. The numerical measure of the APRI score is obtained by using the platelet count as a divisor for the level of AST in the blood. If the AST increases, and the platelet count decreases, the APRI score rises. This can be combined with a second relative test: the ratio of AST in the blood to Alanine Transaminase ("ALT"). Where there is cirrhosis, the AST level increases more than the level of ALT. The change in ratio is thus indicative.

Further information to support a diagnosis could be obtained from ultrasound or CT scans which had already been performed on a patient, and had been recorded in their notes; and where there had been an endoscopy this could show whether there were varices in the gullet. If these were present, they indicated portal hypertension, probably caused by a developing fibrosis of the liver.

Fibrosis is a state of scarring. Scarring by its nature is not flexible. As internal scarring increases, so the flexibility of a liver diminishes. A cirrhotic liver is stiff, whereas a normal liver is pliable and soft. When fibroscans became available, which measured the degree of stiffness in a liver, they were therefore also useful diagnostically. A fibroscan produced a numerical value.<sup>1013</sup>

Before Professor Thomas became a director,<sup>1014</sup> later to be joined by Professor Geoffrey Dusheiko (from 2013 onwards), Nicholas Fish sought advice from Elizabeth Boyd and her contacts at the Royal Free Hospital as to medical issues including whether cirrhosis was present.<sup>1015</sup> His practice was either to accept a claim showing that cirrhosis was established on a balance of probabilities, or to defer it (pending further material showing that there now probably was cirrhosis). Where their applications were deferred, applicants were told that if anything changed, and if they had further tests to rely on, they were welcome to reapply.<sup>1016</sup>

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1011 Professor Howard Thomas Transcript 24 March 2021 pp10-12 INQY1000112

1012 The "platelet count".

1013 Though there was some debate for a while about the figure to be used to indicate probable cirrhosis, eventually a figure of 12 was adopted. There was a difference of recollection about this. Nicholas Fish thought it was 12.5, Professor Thomas thought it was 12, but this was a difference with little distinction, since Nicholas Fish's evidence was that the hepatologist, or both the hepatologists, would evaluate any borderline case in the light of their experience, taking into account all the information about the case including but not limited to the numerical value. Nicholas Fish Transcript 23 March 2021 pp106-113 INQY1000111, Professor Howard Thomas Transcript 24 March 2021 pp31-46 INQY1000112, Written Statement of Professor Geoffrey Dusheiko paras 78.3-78.4, 80.2-80.4 WITN3754048

1014 From late 2012 till the conclusion of the Fund's operations in 2018.

1015 Nicholas Fish Transcript 23 March 2021 p104 INQY1000111, Written Statement of Nicholas Fish para 33.5 WITN4466002

1016 Nicholas Fish Transcript 23 March 2021 p105 INQY1000111

As noted above, where a person infected with Hepatitis C had died, their estate would be entitled to payment if that individual had reached Stage 2 before dying. Since that person might not have been assessed for the presence of cirrhosis during their lifetime, the Fund had to develop a means of determining whether this had probably happened. With the help of Professor Thomas the Fund created a model to help it do this. It distinguished between people who were infected solely with Hepatitis C, on the one hand, and those who were co-infected with HIV on the other – the model estimated the likely speed of progression from infection to cirrhosis, which was faster in the latter group. In March 2013, as fibroscans became more commonly used, the Department indicated they were satisfied with the model of progression which Professor Thomas had created. Some 40 applications from the estates of co-infected people, which had already been determined on the basis that cirrhosis had probably not yet developed, needed to be reviewed in the light of the adoption of the model.<sup>1017</sup> The likelihood is that many had been declined when they should have been accepted.

In summary, the assistance provided through the Skipton Fund to those with Hepatitis C who were not co-infected with HIV was limited.<sup>1018</sup> Progressive changes in the level of payments made to beneficiaries through the national blood support schemes since the Inquiry began, implicitly recognise this.<sup>1019</sup>

## The Skipton Fund Appeals Panel

A body independent of Skipton was set up as an appeal body to reconsider decisions made by the Skipton Fund. The Skipton Fund Appeals Panel held its first meeting on 3 October 2006. It was chaired by Mark Mildred. He was an experienced solicitor who had previously been involved in the litigation brought by people with haemophilia who had contracted HIV, and had informally advised the claimants' legal teams in litigation concerning Hepatitis C and variant Creutzfeldt-Jakob disease, as well as having fulfilled a number of part-time judicial roles.<sup>1020</sup>

The terms of reference for the Appeals Panel notified to Mark Mildred as part of the information pack he received prior to appointment said:

*“The role of the Appeals Panel is to reconsider the cases of any claimants who appeal against individual decisions made by the Skipton Fund. The Panel will look at how the decision was reached and examine all available evidence, or seek further written evidence where necessary, in order to either confirm or change the Skipton Fund’s decision. In considering the evidence the Appeal [sic] Panel will look solely at the written evidence and will not seek personal attendance. The Panel will not be able to consider appeals against the ex-gratia payment*

1017 Minutes of Board of Directors of Skipton Fund Limited meeting 11 March 2013 p3 SKIP0000030\_085, Professor Howard Thomas Transcript 24 March 2021 pp46-50 INQY1000112

1018 People who were co-infected had an application to the Macfarlane or Eileen Trusts available to them. For reasons set out in the chapters on those trusts, this too might be thought limited.

1019 See the chapter on *National Support Schemes*.

1020 Written Statement of Mark Mildred paras 2-11 WITN5258001

*scheme itself, but only examine the process to determine the claims within the terms of the scheme.*

*Appeals may be made against decisions concerning both stage 1 and stage 2 payments. For stage one appeals, the Panel will need to determine whether, on the balance of probabilities, chronic hepatitis C infection resulted from receipt of NHS blood or blood products, and for stage two appeals, the likelihood, on the information provided, that the claimant has developed cirrhosis or primary liver cancer.”<sup>1021</sup>*

The Panel was to consist of five members: a legal professional, three medical members (GP, haematologist and hepatologist) and a lay member. Initially the medical members were Dr John Dracass (the GP member), Dr Hewitt, and Professor David Mutimer. The lay member was Annie Hitchman.<sup>1022</sup>

Mark Mildred was not initially given, nor did he ask for, a copy of the Agency Agreement under which the Skipton Fund operated under the Department of Health.<sup>1023</sup>

It was open to the Appeals Panel to receive evidence over and above that considered by the Fund itself. In contrast with the Fund, it took evidence from applicants, though it did so only in writing: the terms of reference set out above precluded oral testimony. It was not limited to asking whether the decision of the Fund had been reached by an appropriate process but instead exercised its own judgement as to whether, on the evidence available, a claimant appealing against an adverse decision in respect of a Stage 1 payment had probably been infected with Hepatitis C as a result of receiving blood or blood products from the NHS, and whether a claimant appealing against an adverse decision in respect of a Stage 2 payment had probably developed cirrhosis.

In general overview, the Skipton Appeals Panel worked well. It had no hesitation in reaching a conclusion different from that reached by the Office. Indeed, in around half of the cases it did so. The process was relatively informal for an appeal, to its advantage. It was set no targets. It had no budget to which it had to conform. There were no time limits for appealing. There was no set application form by which to do so. The information which was given to it could be added to. The panel met quarterly. A guidance note was provided to applicants.<sup>1024</sup> It made it clear the panel welcomed a personal statement (the Skipton Fund itself did not do so) and allowed for evidence from any witnesses who could give contemporaneous evidence of a transfusion, or its immediate reporting, such as relatives or hospital visitors. The guidance note referred to advice which was said to show that the chance of getting Hepatitis C from even the smallest degree of intravenous drug use was many times greater

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1021 Skipton Fund Appeals Panel Information Pack for Applicants p3 SKIP0000031\_229

1022 In 2009 Dr Dracass retired and was replaced by Dr Norman Gourlay; in 2012 Professor Mutimer retired and was replaced by Professor Peter Mills. Written Statement of Mark Mildred para 13, para 15 WITN5258001

1023 He recalled receiving it a year or so after the Panel was set up. Mark Mildred Transcript 25 March 2021 pp7-8 INQY1000113

1024 Skipton Fund Appeal Guidance NHBT0090738

than the risk of getting Hepatitis C from a transfusion. It did not, however, indicate that a copy of that advice might be obtained from the Office, let alone provide a copy. Nor did it do likewise in respect of intramuscular anti-D.

A particular weakness of the scheme (for which the Appeals Panel itself was not responsible) was the fact that it would not hear evidence from the individual personally.<sup>1025</sup> A further weakness was the habit of the panel giving only short reasons for a refusal. Mark Mildred was accustomed from his work in other contexts, to giving more detailed judgements, but was told by Nicholas Fish when he began work and asked what sort of decision was wanted, to provide “*A letter, keeping it as brief and simple as you can.*”<sup>1026</sup> Sometimes such a letter lacks the detail which makes it possible for an individual to put matters right if part of the reasoning is clearly and demonstrably in error.

In general, however, within the constraints imposed upon it, the independent Appeals Panel acquitted its task well.

## Commentary

This chapter has focused on the particular constraints within which, once established, the Skipton Fund operated. The delay in establishing any form of financial support scheme for those infected with Hepatitis C is considered elsewhere in this Report, as is the inadequacy of the approach of successive governments to the question of compensation.

As set out in the narrative above, there are a number of features of particular concern regarding the application process to the Skipton Fund for the Stage 1 payment.

First, there was no opportunity in the application form or process for applicants to provide any direct evidence themselves (or evidence from friends or family) to demonstrate that they had received blood or blood products prior to September 1991.

Second, a heavy emphasis (which, unfairly, became more onerous still following the fraud perpetrated by the Fund’s first administrator) was placed upon there being records available to show that an individual had received a blood transfusion from which they had become infected with Hepatitis C. The reliance on medical records disadvantaged applicants whose records had been lost or destroyed through no fault of their own and failed to recognise that the absence of a record of transfusion did not mean that no transfusion had taken place – rather it reflected the practical reality that records of transfusions were often not made and/or often not reflected in a GP discharge letter.

Third, this lack of records will inevitably have led to applications being declined when they should not have been, because of a lack of evidence of transfusion or lack of medical records. Although the appeal process worked reasonably well, that was no substitute for

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1025 It would not because it was not permitted to do so: “*In considering the evidence the Appeal [sic] Panel will look solely at the written evidence and will not seek personal attendance.*” Skipton Fund Appeals Panel Information Pack for Applicants p3 SKIP0000031\_229

1026 Mark Mildred Transcript 25 March 2021 p57 INQY1000113



a system which ensured that all relevant evidence could be considered by the Fund in the first instance, and there are likely to have been applicants who did not pursue an appeal but whose applications would have succeeded had the right approach been taken to evidence. There was, moreover, a central flaw in the appeal process, which was the lack of any scope for any kind of oral hearing, which was unfair.

Fourth, in practice the Fund operated a policy which regarded any possibility of intravenous drug use as excluding a claim altogether, in reliance upon the Ramsay Report. This was unfair in two respects: firstly, there was no scope for the individual to be invited to a short hearing where their evidence about possible drug use could be evaluated, and secondly, unsuccessful applicants were not given a copy of the Ramsay Report. This left them ignorant of, and unable to challenge, the detail of the reasoning that had led to the rejection of their claims. The failure to provide Dr Hewitt's letters, on which the Fund relied, to reject anti-D claims, was likewise unfair.

The criteria for qualifying for the Stage 2 payment were, as originally applied, too narrow, with the focus being on a recognised stage of liver disease. They ruled out claims from those who were symptomatic, but who did not yet have cirrhosis, and those who although pre-cirrhotic had undergone treatment which had not only had dreadful side-effects but often gave rise to persisting problems. There was in short insufficient recognition of the severity of the symptoms suffered by those who had not yet developed cirrhosis.

The exclusion of people who had been infected with Hepatitis B was wrong. So too was the exclusion of claims from the bereaved and from estates of those who had died before the scheme was announced. The bright line rule involving a cut-off date of September 1991 was unduly restrictive and unfair without there being the ability to consider exceptional cases. The approach to natural clearers was disjointed and lacking: there was no opportunity for a person to explain why they considered that they had continued to suffer Hepatitis C infection beyond six months, nor could the Fund examine their evidence on the point. Instead too great an emphasis was placed on there being a clear indication in medical records of such signs or symptoms, with an overemphasis on signs. The uncertainties around natural clearers were such at the start of the Fund's operations that there was not only an inconsistency of approach between the Fund's directors for a period of time, but a number of applicants who might have qualified were not put forward by their doctors; and the approach to natural clearers failed to provide for cases in which psychological or psychiatric damage, rather than physiological damage, had resulted.

The responsibility for these failures rests with the Department of Health and not those involved in the day-to-day administration of the Fund which was merely the agent of the Department.<sup>1027</sup>

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<sup>1027</sup> Though responsible as any principal is for the actions of an agent within the scope of their agency, it is nonetheless right to acknowledge that the administrators of the Fund made operational decisions of which the Department may have had little or no knowledge – such as the decision not to offer the Ramsay report to claimants where a decision had been made on the basis of that report.

## 6.8 Government Response to the Archer Inquiry

The Archer Inquiry was an independent, non-statutory inquiry into the supply of infected blood products and its consequences. This chapter examines how the Government reacted to the recommendations of the Archer Inquiry and in particular to the recommendation that there should be financial relief equivalent to that in Ireland.

### Key Dates

**February 2009** Archer Inquiry Report is published.

**May 2009** the Government publishes its formal response to the Archer Inquiry.

**May 2009** Haemophilia Society criticises the Government response.

**July 2009** Minister reiterates that Ireland is different because a judicial inquiry there concluded that wrongful acts had been committed.

**August 2009** campaigner Andrew March issues judicial review proceedings in respect of the Government's response.

**April 2010** ministerial statement brings forward the review of Skipton Fund to as soon as possible this year.

**April 2010** Andrew March's claim for judicial review is successful.

**October 2010** Anne Milton's ministerial statement rejects Lord Archer's recommendation 6(h) that levels of payment here should match those made in Ireland.

**January 2011** Secretary of State announces increase in stage 2 Skipton Fund payments, annual payments for those who reach stage 2, and the establishment of the Caxton Foundation.

### People

**Lord Peter Archer** House of Lords (1992 - 2012), chair of Archer Inquiry

**Andy Burnham** Secretary of State for Health (2009 - 2010)

**Dr Rowena Jecock** head of blood policy, Department of Health

**Gillian Merron** Minister of State for Public Health (2009 - 2010)

**Anne Milton** Parliamentary Under-Secretary of State for Public Health (2010 - 2012)

**Dawn Primarolo** Minister of State for Public Health (2007 - 2009)

**Liz Woodson** director of Health Protection Division, Department of Health

## Recommendations of the Archer Inquiry

The Archer Inquiry was an independent, privately funded, non-statutory inquiry, which was set up, under the chairmanship of Lord Peter Archer, in light of the refusal of successive governments to hold a statutory public inquiry.<sup>1028</sup> Its powers and resources were, in consequence, limited, but its work and findings were nonetheless important. Its report was published on 23 February 2009.<sup>1029</sup> Amongst its conclusions were: that a full public inquiry should have been held much earlier to address the concerns of the haemophilia community;<sup>1030</sup> that there had been “*procrastination in achieving national self-sufficiency to avoid the use of high-risk blood products from overseas*”;<sup>1031</sup> and that “*Commercial priorities should never again override the interests of public health.*”<sup>1032</sup>

The Archer Inquiry made a number of recommendations for future action. These included: the establishment of a statutory committee to advise on the management of haemophilia in the UK; the issue of cards to those who had been infected entitling the holder to benefits not freely available under the NHS; funding for the Haemophilia Society; the making of some provision to ensure patients access to insurance;<sup>1033</sup> and the undertaking of a lookback exercise to identify, as far as possible, individuals who might have been unknowingly infected by infected blood products and who might still not be aware of this.<sup>1034</sup>

Of particular importance was the Archer Inquiry’s recommendation that there should be provided “*Direct financial relief*” for those infected and for carers who had been prevented from working. It was proposed that this scheme of financial relief should take the form of an initial capital sum, followed by prescribed periodical payments; that there should be no distinctions dependent upon the reason for the treatment with blood or blood products; that the anomalies which applied according to the age when the recipient was first infected, or when the infection took place or, in the case of dependents, the date of death of the original patient should be rectified; and that “*payments should be at least the equivalent [sic] of those payable under the Scheme which applies at any time in Ireland.*”<sup>1035</sup>

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1028 This refusal of successive governments is examined elsewhere in this Report. Lord Archer had been an MP between 1966 and 1992 and was a member of the House of Lords between 1992 and 2012. He had been Solicitor General between 1974 and 1979.

1029 Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products 23 February 2009 ARCH0000001

1030 The focus of the Archer Inquiry was on people with haemophilia infected through treatment with blood products.

1031 The Archer Inquiry concluded that had self-sufficiency been achieved earlier, the scale of the catastrophe would have been significantly reduced. The question of self-sufficiency is considered further in the chapter on *Self-Sufficiency*.

1032 Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products 23 February 2009 p107 ARCH0000001

1033 It was suggested that this could be done either by providing the premiums, or by establishing a separate scheme for the patients in question.

1034 Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products 23 February 2009 pp108-111 ARCH0000001

1035 Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products 23 February 2009 pp109-111 ARCH0000001

## Department of Health internal briefings on how to respond to the Archer report

The Department of Health did not have sight of the report in advance of publication.<sup>1036</sup> The day after it was published, on 24 February 2009, Dr Rowena Jecock, who was the head of blood policy within the Department of Health, sent a note to the Minister of State for Public Health, Dawn Primarolo.<sup>1037</sup> The note summarised Lord Archer’s recommendations and set out the policy team’s “*Initial Reactions*” to each of them. On the question of payments, the note stated that a review of the payments system would need to be carefully considered and costed: “*However, the financial implications are enormous if we were to operate in line with the Irish system, as Archer recommends. (An initial estimate applying the average Irish payment to our 4-5,000 cases would be £3-3.5 billion. We need more work to properly quantify these recommendations.)*”. The recommendation regarding access to insurance would be discussed with the Association of British Insurers. If the recommendation for a further lookback exercise were to be implemented it was proposed that this should be managed by the United Kingdom Haemophilia Centre Directors’ Organisation (“UKHCDO”).<sup>1038</sup>

The £3-3.5 billion estimated cost to achieve parity with Ireland was a “*very rough estimate*” and a “*sort of ballpark idea*”.<sup>1039</sup>

The strong recommendation was that there should be no immediate commitment to a timetable for response, and that the necessary consultation, costing of options, and decision time “*may require three months*.”<sup>1040</sup>

The note also included the policy team’s general commentary on the report, saying:

*“There is a suggestion that a secure supply of safer products could have been provided earlier by a faster drive towards self-sufficiency. However, it is debatable how much contamination could have been avoided, given that domestic products could not have been safeguarded against risk of HIV and hepatitis C any sooner than they were.”*<sup>1041</sup>

The Minister of State for Public Health’s Assistant Private Secretary, Morven Smith, annotated the note, adding information on the sums given to the Macfarlane and Eileen Trusts to date and suggesting that, “*In terms of what would be reasonable to give as a one-off additional*

1036 Dr Rowena Jecock Transcript 13 July 2022 p28 INQY1000226

1037 Now Baroness Primarolo. Memo from Dr Rowena Jecock to Dawn Primarolo 24 February 2009 WITN5494033. The covering email is at the bottom of the email chain dated 24-25 February 2009. Email chain between Liz Woodeson, Dr Rowena Jecock, Dr Ailsa Wight and others 24 February 2009 pp2-3 DHSC5561472. Dr Rowena Jecock had asked for input from colleagues across the Department of Health, Department of Work and Pensions, the Medicines and Healthcare Products Regulatory Agency, and officials in Scotland, Wales and Northern Ireland. Email chain between Dr Rowena Jecock and Government officials 24-26 February 2009 DHNI0000175. The memorandum had been cleared by Dr Ailsa Wight, deputy director of the General Health Protection branch in the Health Protection Division of the Department of Health.

1038 Memo from Dr Rowena Jecock to Dawn Primarolo 24 February 2009 p2 WITN5494033

1039 Dr Rowena Jecock Transcript 13 July 2022 p65 INQY1000226

1040 Memo from Dr Rowena Jecock to Dawn Primarolo 24 February 2009 p3 WITN5494033

1041 Memo from Dr Rowena Jecock to Dawn Primarolo 24 February 2009 pp2-3 WITN5494033

payment to the funds; for Macfarlane it would be £7.5-8m.” She also commented at the bottom of the note that:

- *“The Government at the time (1980s) did not accept that there was a case to be answered and did not accept blame. In Ireland, the Government did accept blame and thus offered compensation.*
- *Response to this report does not intend to revisit decision to not accept blame. I asked officials about reasons why the Government of the day did not accept blame – no information about this is held.*
- *Officials are seeking legal advice on how apologising and using the terms ‘health disaster’ might affect us.”<sup>1042</sup>*

In relation to the first of these comments, this reason for distinguishing the position in Ireland (that the Irish Government “*did accept blame and thus offered compensation*”) became a central refrain in the Government’s response to the Archer report. In relation to the second comment, it is surprising to read that “*no information [was] held*” about the reasoning of the Government of the day for not accepting blame – the Department of Health seems to have forgotten that much of the documentation about the Government’s resistance to the HIV litigation should have illuminated this, even though some had gone missing. As for the third point, that officials were seeking legal advice on the effect on the Department of Health of apologising and using the term “*health disaster*” suggests that a primary focus of the Department of Health was the reputational consequence for the Department rather than the position of those whose lives, and the lives of those close to them, had been devastated by infection.

Dawn Primarolo read and annotated the note, commenting, “*This Report is poor I think.*”<sup>1043</sup> Her evidence to the Inquiry was that this comment referred to Dr Rowena Jecock’s report and not to the Archer report itself; she felt disappointed and frustrated by the options provided by officials in response to Lord Archer’s recommendations.<sup>1044</sup> She gave a handwritten instruction to Morven Smith, asking for a note to cover: a brief history of patients being infected; any payments made to them directly; information about the setting up of the Macfarlane, Eileen and Skipton Trusts; the attitude of the Government of the day; how to respond immediately to the request for an apology; how to respond immediately to give additional resources to the Macfarlane and Eileen Trusts (“*How much?*”); and how to take forward consideration of other recommendations. She wrote, “*It is clearly not acceptable in such tragic & unique circumstances for DH to claim no liability and no more money to Trust.*”<sup>1045</sup> A note from around this time, which Baroness Primarolo identified as written by her Private Secretary documenting a discussion between them, recorded similar sentiments

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1042 Memo from Dr Rowena Jecock to Dawn Primarolo 24 February 2009 p3 WITN5494033, Written Statement of Baroness Dawn Primarolo para 2.5 WITN5494001

1043 Memo from Dr Rowena Jecock to Dawn Primarolo 24 February 2009 p1 WITN5494033

1044 Written Statement of Baroness Dawn Primarolo paras 3.86-3.87 WITN5494001, Baroness Dawn Primarolo Transcript 23 September 2022 pp42-43, pp45-46 INQY1000245

1045 Note from Dawn Primarolo to Morven Smith undated p2 WITN5494034

including, “*Proper Report ASAP*”, “*what’s in place 2 never happen again?*” and “*much clearer how much + why fund.*”<sup>1046</sup>

In contrast to the Minister’s instinctive initial reaction, the view of Liz Woodeson, director of Health Protection in the Department of Health, was that the Department of Health should “*aim to do only a brief response and get it out as quickly as possible*”, setting out “*our side of the story – all the steps taken to make the blood supply safer as soon as it was recognised there was a problem*” and all the services provided for people with haemophilia and “*the compensation scheme – anything else positive we can say about what [sic] we are already doing*”, in order to “*politely reject the specific recommendations*”.<sup>1047</sup> It is clear from Liz Woodeson’s email that she was advising the rejection of the recommendations when she had not in fact read the Archer report.<sup>1048</sup>

Dr Ailsa Wight replied saying that she thought money rather than services would be the “*main issue*”, and that she suspected that the Minister “*will want to offer something.*”<sup>1049</sup>

On 25 February 2009 Morven Smith responded to Dr Rowena Jecock’s initial note, asking for the information set out in the Minister’s handwritten instruction and explaining that:

*“MS(PH) [Minister of State for Public Health] has seen this report and is very concerned about the contamination of NHS blood and blood products during the 1970s and 1980s. She is particularly concerned about how this issue has been handled.*

*The Minister feels that it is clearly not acceptable in such tragic and unique circumstance for DH [Department of Health] to claim no liability and to give no more money to the Trusts.”*<sup>1050</sup>

As requested, Dr Rowena Jecock supplied a further note the following day on 26 February 2009.<sup>1051</sup> She said that the Archer report was critical of the speed of response of the NHS and government to the threats of contamination of blood and blood products, adding that “*We do not accept all his criticisms, but official documents do show problems at various times in*

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1046 Note from Sarah Kirby to Dawn Primarolo undated WITN5494115, Baroness Dawn Primarolo Transcript 23 September 2022 pp50-51 INQY1000245

1047 Email chain between Liz Woodeson, Dr Rowena Jecock, Dr Ailsa Wight and others 25 February 2009 p2 DHSC5561472

1048 This is both a surprising and a disappointing approach from the Department of Health’s director of Health Protection. It is right to note that Liz Woodeson was responding whilst abroad on leave, and plainly felt under pressure of time to respond.

1049 Deputy director of the General Health Protection branch in the Health Protection Division. Email chain between Liz Woodeson, Dr Rowena Jecock, Dr Ailsa Wight and others p1 DHSC5561472

1050 Email chain between Morven Smith, Dr Rowena Jecock, Dr Ailsa Wight and others 25 February 2009 p4 DHSC5017972. The Minister also wanted to request approval to speak to former ministers regarding this issue. Morven Smith clarified in a follow-up email that she “*did not mean to imply that the Minister was unhappy about the team’s handling of the publication of Lord Archer’s report*” but rather “*the handling of the issue as whole in an historical context as well as how we came to the position we are at now.*” Email chain between Morven Smith, Dr Rowena Jecock, Dr Ailsa Wight and others 25 February 2009 p2 DHSC5017972

1051 Note from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 DHSC0011467. This was again approved by Dr Ailsa Wight.

*the development of UK capabilities for manufacture of blood products*” and acknowledging the judgment in *A and Others v National Blood Authority*, where the judge “commented that the UK could have introduced screening or surrogate tests for hepatitis C earlier than it did.”<sup>1052</sup> The Minister’s questions were addressed and a limited chronology provided.<sup>1053</sup> It was suggested that a statement “expressing this Government’s regret at the events that occurred and the consequences for those affected” could be drafted,<sup>1054</sup> and that although “the term ‘health disaster’ is too strong a term, as if the available blood products had not been employed, patients may have died even earlier than they did” a form of wording such as “a tragedy for those affected” could be offered.<sup>1055</sup> The briefing also noted that an intention to review “perceived anomalies” between the three Trusts could be announced at an early stage “ahead of the Government’s substantive response to the report.”<sup>1056</sup> Dr Rowena Jecock provided a draft note to be provided from the Minister to the Secretary of State summarising the suggested response,<sup>1057</sup> which the Minister subsequently annotated with the comment, “What about more money?”<sup>1058</sup>

Dawn Primarolo met officials from the Health Protection team working on blood policy on 2 March 2009.<sup>1059</sup> Following the meeting, the team were tasked with providing further information and analysis in order to formulate a response to the Archer report.<sup>1060</sup> Amongst other things, the Minister wished to have a reassessment of the argument not to have a public inquiry and to know “How is the ROI [Republic of Ireland] scheme going? why [sic] did they decide to accept liability” and “An idea of what money would be reasonable to give to MFT [Macfarlane Trust], ET [Eileen Trust] and Skipton Fund.”<sup>1061</sup> In relation to the latter, it was noted that, “MS(PH) has grave concerns about the long term implications of a final settlement figure for these schemes.”<sup>1062</sup> Baroness Primarolo told this Inquiry

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1052 Note from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 p1 DHSC0011467

1053 The chronology made no reference either to the 1978 Preston study, or to Dr Diana Walford’s September 1980 minute. The sole reference for 1980 was an October 1980 entry referring to Dr John Craske stating that “NANBH [non-A non-B Hepatitis] is mild and often asymptomatic, but might cause chronic liver disease”, and suggesting that in 1982 “Studies begin to indicate that NANBH is more serious than previously thought”. Note from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 p17 DHSC0011467. As will be apparent from the chapter on *Hepatitis Risks 1970 and After* this was not an accurate account.

1054 Note from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 p1 DHSC0011467

1055 Note from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 p11 DHSC0011467

1056 Note from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 p1 DHSC0011467

1057 Note from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 pp15-16 DHSC0011467

1058 Note from Dawn Primarolo to Alan Johnson 26 February 2009 WITN5494037. Morven Smith also sent further follow-up questions on the Minister’s behalf in emails of 26 February 2009. Email chain between Morven Smith, Dr Rowena Jecock and others 26 February DHSC0011469, Email chain between Dr Rowena Jecock, Morven Smith and others 26 February 2009 DHSC5561857

1059 An email from Morven Smith to the officials working on blood policy titled “Lord Archer Inquiry Meeting – Action Points” dated 2 March 2009 describes this meeting. Email from Morven Smith to Dr Ailsa Wight, Dr Rowena Jecock, Liz Woodeson and others 2 March 2009 DHSC6120809

1060 Baroness Dawn Primarolo Transcript 23 September 2022 p68 INQY1000245

1061 Email from Morven Smith to Dr Ailsa Wight, Dr Rowena Jecock, Liz Woodeson and others 2 March 2009 p2 DHSC6120809

1062 Email from Morven Smith to Dr Ailsa Wight, Dr Rowena Jecock, Liz Woodeson and others 2 March 2009 p2 DHSC6120809

her concern had been that final settlements may not take account of future health and support requirements.<sup>1063</sup>

### Political pressure to respond

Meanwhile, there was a degree of external pressure on the Department of Health to provide its response. On 3 March 2009, Edward O’Hara MP tabled an Early Day Motion: *“That this House welcomes the publication of the Archer Report on the use of contaminated blood and blood products in NHS treatments and hopes that the victims of the use of such products will receive swift and appropriate recompense; and calls on the Government to make a full and speedy response to the report’s findings and to make a commitment to implement its recommendations as soon as possible.”*<sup>1064</sup>

On 5 March 2009, Baroness Glenys Thornton, Parliamentary Under-Secretary of State for Health in the Lords, answered a Parliamentary Question from Lord Alf Morris about when the Government expected to respond to the Archer report:

*“we take this issue very seriously. We will respond when we have given the report of my noble and learned friend Lord Archer the consideration that it deserves. While successive Governments have acted in good faith, the serious infections inadvertently contracted by those patients as a result of their treatment have had tragic consequences. I am deeply sorry that this has happened. These events were the subject of long-concluded legal proceedings, and the Government have established three schemes to provide financial assistance to those affected.”*<sup>1065</sup>

The reference to infections being *“inadvertently contracted”* was no doubt intended to suggest that this was something unavoidable, for which the Government could not be held responsible.

Similarly, on 6 March 2009, Dawn Primarolo answered a Parliamentary Question in the House of Commons from Danny Alexander MP about whether compensation would be paid to people with haemophilia infected with Hepatitis C and HIV by outlining the existing schemes and saying, *“The Department is giving Lord Archer’s report the consideration it deserves and will respond as soon as it has done so.”*<sup>1066</sup>

### Meeting between Lord Archer and ministers on 11 March 2009

The Secretary of State for Health, Alan Johnson,<sup>1067</sup> together with Dawn Primarolo, met Lord Archer on 11 March 2009. In advance of the meeting, Dr Rowena Jecock and her team

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1063 Baroness Dawn Primarolo Transcript 23 September 2022 p66 INQY1000245

1064 Early Day Motion on Archer Report into Contaminated Blood and Blood Products 3 March 2009 DHSC0041157\_053

1065 Hansard House of Lords Official Report 5 March 2009 p6 HSOC0017176, with the answer having been suggested in: Lord’s Oral Questions Briefing Pack 5 March 2009 p3 MHRA0024712

1066 Hansard parliamentary question on Blood Contamination 6 March 2009 p1 DHSC5579192

1067 Alan Johnson was Secretary of State for Health between June 2007 and June 2009.



provided a briefing.<sup>1068</sup> It set out the Government’s position as including the following: that while “*this is a tragedy and there is every sympathy for those infected*”, the treatment given to people with haemophilia “*was the best available at the time and action was taken in good faith*”; technologies to improve safety (heat treatment and testing) had been introduced as soon as available; that in relation to Hepatitis C the “*very severe long term consequences of infection were only fully recognised by the scientific community during the late 1980s*”, special payments had already been set up; and there had been no admission or finding of negligence by the state.<sup>1069</sup> The briefing noted that several of Lord Archer’s recommendations were based on measures that had been implemented in Ireland, and stated that:

*“The situation in the UK is different to that in Ireland, where it was acknowledged that action to reduce the risk could have been taken earlier. The Irish Blood Service issues an apology acknowledging ‘failures’ in the past and their payment regime reflects this admission of mistakes.”*<sup>1070</sup>

Lord Archer’s recommendations were not supported, save to the extent that the recommendation regarding access to insurance was to be discussed with the Association of British Insurers.<sup>1071</sup> The costs of various options for changing the trusts and schemes were outlined.<sup>1072</sup>

The Government’s line that patients received the best available treatment at the time, and the line that testing was introduced as soon as available, are discussed elsewhere in this Report: but in short, neither was true.<sup>1073</sup>

Baroness Primarolo’s evidence to this Inquiry was that she was “*extremely disappointed*” by the suggested responses to the Archer recommendations,<sup>1074</sup> and her contemporaneous handwritten annotations on the briefing include comments suggesting she was frustrated with the lack of positive options; “*no pension because couldn’t work low income clearly identifiable need.*”<sup>1075</sup>

At the meeting with Lord Archer, he summarised the three main recommendations from his report as being: establishing a new committee to advise the government on haemophilia, providing funding to keep the Haemophilia Society afloat, and reassessing financial relief for those affected.<sup>1076</sup> A summary of the discussion produced after the meeting recorded that:

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1068 Note from Dr Rowena Jecock to Penelope Irving and Morven Smith 10 March 2009 DHSC0041157\_052

1069 The *A and Others v National Blood Authority* litigation having succeeded, it was said, under strict liability consumer protection legislation: Note from Dr Rowena Jecock to Penelope Irving and Morven Smith p2 DHSC0041157\_052

1070 Note from Dr Rowena Jecock to Penelope Irving and Morven Smith p6 DHSC0041157\_052

1071 Note from Dr Rowena Jecock to Penelope Irving and Morven Smith pp7-8 DHSC0041157\_052

1072 Note from Dr Rowena Jecock to Penelope Irving and Morven Smith pp12-17 DHSC0041157\_052

1073 See chapter on *Lines to Take*

1074 Written Statement of Baroness Dawn Primarolo para 3.110 WITN5494001

1075 Note from Dr Rowena Jecock to Penelope Irving and Morven Smith p1 DHSC0041157\_052

1076 See email from Penelope Irving, Assistant Private Secretary to the Secretary of State for Health, to various officials in the Department of Health, summarising the discussion that took place at

*“SoS [Secretary of State for Health] would need to be convinced that current financial arrangements were insufficient before he considered any adjustments to the compensation system. Lord Archer explained that many patients suffered financial hardship but MS(PH) [Minister of State for Public Health] said it was important to distinguish what financial pressures were a consequence of infection, as opposed to being the consequence of the illness which had caused the patients to need transfusion in the first place i.e. haemophilia.”*<sup>1077</sup>

In his written evidence to this Inquiry, Alan Johnson stated that in saying he needed to be convinced, he was not ruling out increased funding but “*sounding a note of caution*” in the context of a difficult financial climate.<sup>1078</sup>

Following the meeting, ministers requested further advice from officials on the eligibility criteria under the different schemes, including options to rationalise the schemes, options for insurance provision, funding for the Haemophilia Society, and the possibility that the Haemophilia Society could be given a wider remit as an alternative to adopting Lord Archer’s recommendation to establish a new committee.<sup>1079</sup>

On 17 March 2009, an amendment to the Health Bill tabled by Lord Morris and Lord Robin Corbett to establish a committee on haemophilia as recommended by Lord Archer was debated.<sup>1080</sup> The amendment was withdrawn but Lord Morris stated his intention to raise it again at the report stage in late April.<sup>1081</sup>

### **Further internal discussions on the Government’s response**

On 19 March 2009, Dr Rowena Jecock provided ministers with the briefing requested.<sup>1082</sup> The briefing advised that addressing anomalies in the eligibility criteria in the Skipton Fund would cost in the order of £56m, and that rationalising the Macfarlane and Eileen Trusts and removing the discretionary element would cost around £100m.<sup>1083</sup>

Baroness Primarolo’s evidence to this Inquiry was that the sums involved were higher than she had anticipated, and she knew that, given the financial constraints to which the Department of Health was subject, a cost of £50m or £100m was not achievable.<sup>1084</sup>

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the meeting of 11 March 2009 with Lord Archer. Email from Penelope Irving to Dr Ailsa Wight, Dr Rowena Jecock and others 13 March 2009 DHSC0006756

1077 Email from Penelope Irving to Dr Ailsa Wight, Dr Rowena Jecock and others 13 March 2009 p3 DHSC0006756

1078 Written Statement of Alan Johnson para 3.17 WITN7197001

1079 Email from Penelope Irving to Dr Ailsa Wight, Dr Rowena Jecock and others 13 March 2009 p3 DHSC0006756

1080 Amendment by Lord Morris and Lord Corbett 17 March 2009 DHSC5177210

1081 Memo from Dr Rowena Jecock to Alan Johnson and Dawn Primarolo 19 March 2009 p1 WITN5494098

1082 Memo from Dr Rowena Jecock to Alan Johnson and Dawn Primarolo 19 March 2009 WITN5494098

1083 Memo from Dr Rowena Jecock to Alan Johnson and Dawn Primarolo 19 March 2009 pp1-2 WITN5494098

1084 Written Statement of Baroness Dawn Primarolo para 3.116 WITN5494001. In her oral evidence, she spoke about the context of the 2008 financial crash and spending limits on all Government

In relation to the Haemophilia Society, the briefing advised that the Society could be provided with a development grant of £100,000, but that “*We do not believe it would be appropriate to simply prop up the Haemophilia Society through ongoing core funding.*” Dawn Primarolo annotated this recommendation, “*Disagree. Haem. Society is unique we should fund.*”<sup>1085</sup> In relation to Lord Archer’s recommendation for a new committee to advise on haemophilia, the suggestion was that “*We explore further the options for involving the Haemophilia Society more formally in advising on safe and effective use of blood products.*”<sup>1086</sup>

On 24 March 2009, Morven Smith emailed an official in the Health Protection Division with an outline of Dawn Primarolo’s thinking; she wished to give recurrent funding to the Macfarlane and Eileen Trusts and do away with discretionary payments but leave the Skipton Fund alone, “*with a caveat that we will review the situation of the SF in 2014 which is ten years after inception.*”<sup>1087</sup>

Dr Rowena Jecock and her team provided a further briefing on 31 March 2009. The briefing noted that the Minister’s preferred approach was to replace the discretionary element in Macfarlane and Eileen Trust payments, harmonise the level of lump sum payments made by these Trusts, and increase the level of funding to the Trusts. This was estimated to cost £19m as a one-off sum and then an additional £2.1m per year. Bringing the eligibility criteria for the Skipton Fund in line with the two Trusts by including dependents bereaved before the inception of the Fund was estimated to cost £54m and would require approval from the devolved administrations. The Treasury would not provide any additional funding.<sup>1088</sup>

The Minister was unhappy with this submission<sup>1089</sup> and on 6 April 2009, Morven Smith wrote on her behalf to Dr Rowena Jecock and Liz Woodeson requesting a set of proposals giving options of how to approach each of Lord Archer’s recommendations “*in the most positive way possible.*”<sup>1090</sup>

Liz Woodeson authored the next submission on the topic, on 17 April 2009, which did as requested address each of Lord Archer’s recommendations with one or more positive options,

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departments. Baroness Dawn Primarolo Transcript 23 September 2022 p76 INQY1000245

1085 Memo from Dr Rowena Jecock to Alan Johnson and Dawn Primarolo 19 March 2009 p2 WITN5494098. Baroness Primarolo confirmed this was her handwriting. Baroness Dawn Primarolo Transcript 23 September 2022 p74 INQY1000245

1086 Memo from Dr Rowena Jecock to Alan Johnson and Dawn Primarolo 19 March 2009 p4 WITN5494098

1087 Email from Morven Smith to Brian Bradley 24 March 2009 p1 DHSC5024869. Baroness Primarolo stated in her evidence to this Inquiry that at the time this email was sent she had been under time pressure to announce the Government response and the Skipton Fund was “*a particularly complex one to unpack*” so she took the decision to put it to one side, while setting a review for the 10-year point. Baroness Dawn Primarolo Transcript 23 September 2022 p77 INQY1000245

1088 Memo from Dr Rowena Jecock to Dawn Primarolo 31 March 2009 pp1-3 DHSC0041157\_035. The briefing also considered Lord Archer’s other recommendations. Discussions with the British Association of Insurers were ongoing, but it was suggested that increasing the level of payments available through the financial relief schemes may address the main concerns about the ability to pay insurance premiums. The UKHCDO was said to see utility in a lookback exercise in relation to Hepatitis C, which was estimated to cost in the region of £50,000.

1089 Written Statement of Baroness Dawn Primarolo para 3.126 WITN5494001

1090 Email from Morven Smith to Dr Rowena Jecock and Liz Woodeson 6 April 2009 p2 DHSC5567182

if not a straightforward acceptance, included in response to each of them.<sup>1091</sup> In relation to the Haemophilia Society, additional options of maintaining core funding, or offering five years' core funding, were included.<sup>1092</sup> The Minister preferred the latter option.<sup>1093</sup> In relation to the Skipton Fund, it was noted that the Minister had already decided that this should be left alone pending a review in 2014.<sup>1094</sup> However, the possibility of correcting the anomaly in eligibility for partners and dependents bereaved prior to the establishment of the Fund was included as an option, albeit with the caveat that the £54m costs was "*a very large sum and reaching agreement with [the Treasury] and the [Devolved Administrations] would be challenging.*"<sup>1095</sup> In relation to the Macfarlane and Eileen Trusts, options to increase annual payments to either £10,000 or £12,800 per year were laid out.<sup>1096</sup> Dawn Primarolo preferred the latter option.<sup>1097</sup>

In giving her evidence to this Inquiry, Dr Rowena Jecock agreed that the figure of £12,800 was arrived at on the basis of what was affordable and politically the ministers could "*live with*"; there was no assessment of need and in that sense the figure was arbitrary.<sup>1098</sup>

### Ongoing pressure to respond and submission to the Secretary of State

Meanwhile, there continued to be pressure on the Government to provide its response to the Archer report. On 2 April 2009, Dr Rowena Jecock had provided a briefing for Dawn Primarolo explaining the difficulties that Lord Archer's report created for the passage of the Health Bill, in particular that "*in the absence of any indicative Government response to Lord Archer's recommendations*", the Government risked losing a vote on Lord Morris' retabled amendment in the House of Lords.<sup>1099</sup>

On 21 April 2009, Jenny Willott MP asked a parliamentary question on the timetable and mechanism for responding, and Dawn Primarolo replied that the recommendations were "*receiving very careful consideration, and we will respond in due course.*"<sup>1100</sup>

On 23 April 2009, there was a debate in the House of Lords on a motion proposed by Lord Morris, "*To call attention to the findings of the Independent Public Inquiry headed by Lord*

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1091 Memo from Liz Woodeson to Dawn Primarolo 17 April 2009 WITN5494052. Morven Smith commented in a cover note of the same date "*These responses to recommendations seem much more robust and better incorporate your preferences.*" Note from Morven Smith to Dawn Primarolo 17 April 2009 p1 WITN5494054

1092 Memo from Liz Woodeson to Dawn Primarolo 17 April 2009 p3 WITN5494052

1093 See her handwritten comment, "*Agreed*". Note from Morven Smith to Dawn Primarolo 17 April 2009 p2 WITN5494054

1094 Memo from Liz Woodeson to Dawn Primarolo 17 April 2009 p3 WITN5494052

1095 Memo from Liz Woodeson to Dawn Primarolo 17 April 2009 p4 WITN5494052

1096 Memo from Liz Woodeson to Dawn Primarolo 17 April 2009 p3 WITN5494052

1097 See handwritten annotations: Note from Morven Smith to Dawn Primarolo 17 April 2009 pp2-3 WITN5494054, Baroness Dawn Primarolo Transcript 23 September 2022 p86 INQY1000245

1098 Dr Rowena Jecock Transcript 13 July 2022 p78 INQY1000226

1099 Memo from Dr Rowena Jecock to Morven Smith 2 April 2009 p2 DHSC0041157\_015

1100 Hansard written answer to parliamentary question on Contaminated Blood Products 21 April 2009 DHSC0006241\_026

*Archer of Sandwell into the infection and deaths of patients with HIV and hepatitis C by contaminated National Health Service blood and blood products*".<sup>1101</sup> On 28 April 2009, Lord Morris moved his amendment to the Health Bill during its report stage.<sup>1102</sup> He agreed to withdraw it upon Lord Ara Darzi, Parliamentary Under-Secretary of State for Health in the Lords, undertaking to do everything possible to ensure that the Government responded fully to Lord Archer's recommendations before the Whitsun recess.<sup>1103</sup>

The Minister provided a formal minute to the Secretary of State on 23 April 2009. Amongst her suggested responses to Lord Archer's recommendations were:

- *"That we leave the payments under the Skipton Fund for those infected with hepatitis C the same as they are now but announce we will review this in 2014 – ten years after the Fund was set up.*
- *That we change the system of payments made by the Macfarlane and Eileen Trusts to those infected with HIV to remove the discretionary element and give all recipients the same amount every year. And that we double the current average annual amount from £6,400 a year<sup>1104</sup> to £12,800 per year. This will cost around £7.6m per year in total – a total increase of £3.8 m per year. We will need to note this with Treasury both as a formal commitment of future spending reviews, but also to ensure consistency with wider public finance protocols.*
- *That we do not rectify any of the anomalies within and between the schemes. To rectify the main anomaly in the Skipton Fund would cost up to £54m and even to harmonise the lump sum payments between the two other Trusts would cost £19m.*
- *That the increased payments for Macfarlane and Eileen Trust recipients will help them to meet the increased insurance premiums they face. That we will continue to discuss the insurance issue with the Association of British Insurers.*
- *That we will carry out a look back exercise to try and identify any other patients with bleeding disorders who might be unknowingly infected. (This will cost around £50k)."*<sup>1105</sup>

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1101 Lord's Debate Briefing Pack DHSC0006615\_008, Hansard parliamentary debate on Health Contaminated Blood Products 23 April 2009 HSOC0002256

1102 Opposition Amendment on Creation of a Committee to advise on Haemophilia 28 April 2009 DHSC5018019

1103 Hansard Health Bill Amendment on the Advisory Committee on the Treatment of Haemophilia 28 April 2009 DHSC0011434. The Whitsun Recess date in the House of Lords was 21 May 2009.

1104 Note that the Department's calculation of a £6,400 per annum average payment per recipient was not accepted by all stakeholders; see for example an internal brief for a meeting with the chairs of the Macfarlane Trust and Eileen Trust and Skipton Fund, anticipating their criticisms of this calculation. Brief for meeting with Christopher FitzGerald and Peter Stevens 15 July 2010 p1 WITN6437005

1105 Memo from Dawn Primarolo to Alan Johnson 23 April 2009 pp1-2 WITN5494055

She noted that this package of measures would not satisfy Lord Archer and his supporters entirely, and in particular there might be significant criticism from the Hepatitis C community of the decision to make no changes to the Skipton Fund, but that it would show they were “*doing all we realistically can.*”<sup>1106</sup> Baroness Primarolo told this Inquiry that the sole reason why the anomaly in the Skipton Fund was not addressed was the cost.<sup>1107</sup>

On 25 April 2009, the Secretary of State annotated the minute, “*Agreed. Good outcome if not all that Lord A would want.*”<sup>1108</sup>

## Government report in response to the Archer Inquiry

The Government’s formal report in response to the Archer Inquiry<sup>1109</sup> was notified to Lord Archer on 19 May 2009,<sup>1110</sup> and published with a written ministerial statement<sup>1111</sup> on 20 May 2009.<sup>1112</sup> The report responded to each of Lord Archer’s recommendations in accordance with the position agreed by ministers:

- The recommendation to establish a statutory committee to advise the Government on the management of haemophilia was not adopted but the Government offered to meet with the Haemophilia Alliance on a twice-yearly basis instead.<sup>1113</sup>
- The recommendation that haemophilia patients and their partners should receive any tests recommended by the statutory committee was adapted to say instead that “*Any new relevant tests for transfusion transmitted infections would be offered to haemophilia patients, and their partners, in light of advice from the Haemophilia Alliance.*”<sup>1114</sup>

1106 Memo from Dawn Primarolo to Alan Johnson 23 April 2009 p2 WITN5494055. Emphasis in the original.

1107 Baroness Dawn Primarolo Transcript 23 September 2022 pp88-89 INQY1000245

1108 Memo from Dawn Primarolo to Alan Johnson 23 April 2009 p1 WITN5494055 and Written Statement of Alan Johnson para 3.31 WITN7197001

1109 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 DHSC0015670. The response relied, in part, on the Department of Health’s own report titled *Self-Sufficiency in Blood Products in England and Wales: a Chronology from 1973 to 1991* 2006 DHSC0200111, which is considered elsewhere in this Report.

1110 Letter from Dawn Primarolo to Lord Archer dated 19 May 2009 DHSC0041240\_070. Similar letters went to Lord Morris, the chief executive of the Haemophilia Society Chris James and the chair of the All-Party Parliamentary Group on Haemophilia Edward O’Hara MP. Letter from Dawn Primarolo to Lord Morris 19 May 2009 HSOC0012580\_002, Letter from Dawn Primarolo to Chris James 19 May 2009 DHSC0041240\_072, Letter from Dawn Primarolo to Edward O’Hara 19 May 2009 DHSC0041240\_073

1111 Response to Lord Archer’s independent inquiry report on NHS supplied contaminated blood and blood products 20 May 2009 WITN1056096

1112 See also Government Press Release *Government responds to Archer Inquiry: Financial assistance for HIV patients will double* DHSC0041219\_125, Archer Report on Contaminated Blood Q&A WITN5494099 and briefing pack for the Parliamentary Labour Party Government response to the Archer Inquiry 27 May 2009 ARCH0001160. The approach to communicating the Government’s response was planned in submissions dated 13 May 2009 (Memo from Deborah Webb to Alan Johnson DHSC0041307\_029) and 18 May 2009 (DH Media Handling Plan for Government response to Archer Inquiry DHSC0041219\_124 and Memo from Deborah Webb to Alan Johnson DHSC0041219\_127).

1113 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p9 DHSC0015670

1114 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p9 DHSC0015670

- The recommendation that all blood donors should also receive the same tests recommended by the statutory committee was rejected on the basis that the independent advisory committee on the Safety of Blood, Tissues and Organs already advised on tests for blood donors.<sup>1115</sup>
- The recommendation that those infected should be provided with cards entitling them to benefits not freely available under the NHS, including “*free of charge prescription drugs, general practitioner visits, counselling, physiotherapy, home nursing and support services*”<sup>1116</sup> was not adopted, save that it was noted that prescription charges for patients with long term conditions were already the subject of an ongoing review. GP, counselling, physiotherapy and home nursing services were considered to already be available free of charge through the NHS, and other support services, such as domiciliary care, were a matter for local authorities.<sup>1117</sup>
- The recommendation to secure the future of the Haemophilia Society by adequate funding was accepted to the extent that the Government pledged to provide £100,000 per annum for the next five years.<sup>1118</sup>
- The recommendation concerning financial assistance was addressed by funding increased annual payments of £12,800 to those infected with HIV from the Macfarlane and Eileen Trusts and removing the discretionary element of those payments. Payments to their families would remain at the discretion of the trustees. However, no changes were made to the Skipton Fund. A commitment was made to review the fund at its ten-year anniversary in 2014.<sup>1119</sup> (Significantly, the recommendation that payments should be at least the equivalent of those payable under the scheme which applied at any time in Ireland, was not expressly referred to and not adopted. However a Q&A briefing gave the following proposed answer in the event of the question being raised:

*“Payments made by the Republic of Ireland are a matter for them and were in response to particular circumstances in Ireland relating to the use of blood products. The situation in the UK was different. Action was taken as soon as possible to introduce testing and safety measures for blood and blood products as these became available. The introduction of heat treated product in 1985 was a key factor in protecting our supply. The establishment*

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1115 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p9 DHSC0015670

1116 Independent Public Inquiry Report on NHS Supplied Contaminated Blood and Blood Products 23 February 2009 p109 ARCH0000001

1117 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p10 DHSC0015670

1118 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p10 DHSC0015670

1119 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p11 DHSC0015670. Dr Rowena Jecock stated in evidence that the reason why the decision in relation to those infected with Hepatitis C was deferred until 2014 was affordability. Dr Rowena Jecock Transcript p82 13 July 2022 INQY1000226

*of the ex-gratia payment schemes in the UK was in recognition of the special and unfortunate position of those who were inadvertently infected.”<sup>1120)</sup>*

- The recommendation regarding access to insurance was not adopted on the basis that insurability depended on individual risk as for anyone with a pre-existing condition, but the *“increased payments we are making available will help people infected with HIV to meet higher insurance premiums they may face.”<sup>1121</sup>*
- The recommendation to conduct a lookback exercise was accepted and would be undertaken by the UKHCDO.<sup>1122</sup>

In the section of the response titled *“Support and services for those affected – the future”*, it was stated that, *“We have carefully considered Lord Archer’s recommendations, and are responding in as positive a way as possible at the current time, bearing in mind the constraints on public funds.”<sup>1123</sup>*

In his judgment in a subsequent legal challenge to the Government’s response, Mr Justice James Holman commented in relation to this passage that *“Peeling away the jargon, that is the government saying that they are proposing to pay as much as they judge, as a matter of policy and politics, they can currently afford to allocate to this particular need.”<sup>1124</sup>*

## Reactions to the Government report

On the same day the report was published, Chris James, chief executive of the Haemophilia Society, issued a press release fiercely criticising the response to the Archer Inquiry, saying that *“by not implementing the recommendations in full, [the Government] shows its contempt for the victims”* and calling the proposals *“a collection of half measures.”<sup>1125</sup>*

Dawn Primarolo convened a meeting with civil servants on 21 May 2009 to discuss the reaction to the Government’s response.<sup>1126</sup> An email summary of the meeting written on the same day recorded, amongst other points:

- *“MS(PH) expressed serious concern over the reaction to the Response especially from the Haemophilia Society. The team confirmed that they were shocked at the Haemophilia Society’s response also – there had been no indication from them that it would be such a vitriolic response.*

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1120 Archer Report on Contaminated Blood Q&A p32 WITN5494099

1121 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p12 DHSC0015670

1122 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p12 DHSC0015670

1123 Government response to Lord Archer’s Independent report on NHS supplied contaminated blood and blood products 20 May 2009 p8 DHSC0015670

1124 *R (March) v Secretary of State for Health* 16 April 2010 para 13 DHSC0003819\_011

1125 Email from Dan Farthing to Jane Dreaper 20 May 2009 WITN5494100. Email from Dr Rowena Jecock to Morven Smith and others 1 June 2009 p3 DHSC0041219\_087

1126 Email from Morven Smith to Dr Rowena Jecock and others 21 May 2009 DHSC5585213



- *MS(PH) asked why we haven't accepted liability as Ireland have and asked for this to be investigated. She said that we need to separate ourselves from the comparison with Ireland in order to get a positive message across. People need to understand why the UK case is different to Ireland. The team agreed to produce substantive information and defence on this point for future use including information on the litigation case in UK in 1990s and how this differs from Ireland in order to make the case for reasonable payments.*

...

- *MS(PH) said that if it transpired that money needed to go to the Skipton Fund then we would need to revisit this with Finance colleagues.*
- *Judith [Moore] noted that we have to be mindful that by waiting until 2014 to review it may look like we are waiting for more recipients to die before reviewing the money being given.*

...

- *MS (PH) stated that she was uncomfortable with a monetary argument versus a moral argument."*

Lord Archer replied by letter of 22 May 2009. He wrote:

*"While some of the Government's proposals were, frankly, disappointing, for example the absence of any increase in financial relief for beneficiaries of the Skipton Fund until 2014, the indifference to the limitations in the entitlement of widows, and the suggestion that after five years, the Haemophilia Society 'will be expected to have in place an effective strategy to meet its future funding plans', as though it were a commercial enterprise, some of the proposals are more positive, and I would have hoped that they could have been presented in a more positive setting.*

*When Parliament re-assembles I hope to conduct discussions between the various parties in a less emotive and confrontational atmosphere, which will also ensure that the Government receives some credit for its recognition of the hardships suffered by the patients."*<sup>1127</sup>

Baroness Primarolo's written evidence to this Inquiry was that *"In some ways, the negative reaction to the Government's response to Lord Archer's Report was helpful because it gave me a lever to try to see if more could be done."*<sup>1128</sup> She added in oral evidence that her continuing objective in the period after the response had been published was *"to find the best possible solution within all the constraints that of course exist for a minister and a department."*<sup>1129</sup>

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1127 Letter from Lord Archer to Dawn Primarolo 22 May 2009 DHSC0041219\_095

1128 Written Statement of Baroness Dawn Primarolo para 3.146 WITN5494001

1129 Baroness Dawn Primarolo Transcript 23 September 2022 p97 INQY1000245

On 1 June 2009, Dr Rowena Jecock and her team provided a briefing on “*Government response to Lord Archer – next steps*”. This noted the reaction to the package announced in response to the Archer report had been “*limited, but negative.*” Three highlighted areas of criticism were: the level of payments to HIV patients; absence of any uplift for Hepatitis C patients; and that in respect of both “*The level of payments should be closer to the amounts paid in Ireland which are claimed to be an average of £1m per person ... and up to £5m per person in some cases*”. The briefing advised that the situation in Ireland could be distinguished on the basis that “*The Government here has never accepted any liability. We believe that people were offered the best treatment available at the time and that as soon as blood screening tests were available they were implemented.*” The projected costs of making annual payments to Skipton Fund claimants in a variety of ways were also set out.<sup>1130</sup> Morven Smith replied to this submission on Dawn Primarolo’s behalf asking for more information, and in particular regarding the substantive reasons why the situation in Ireland was thought to be so different from that in the UK.<sup>1131</sup>

Dr Rowena Jecock followed up with a further submission on 2 June 2009. This gave further details, stating that “*In Ireland also, the State did not explicitly admit liability*” but that a judicial inquiry, the Finlay Inquiry, had concluded that “*wrongful acts were committed*” in respect of failure to prevent Hepatitis C infections.<sup>1132</sup> Officials’ recommendation was to “*hold... the line*” and not make changes to the Skipton Fund.<sup>1133</sup>

## Change of ministerial team in the Department of Health

However, before Dawn Primarolo had made any decision on the 2 June 2009 submission, she was moved to become Minister of State at the Department for Children, Schools and Families in a reshuffle that followed the local and European elections on 4 June 2009. She was replaced by Gillian Merron (later Baroness Merron). At the same time, Alan Johnson became Home Secretary and Andy Burnham replaced him as Secretary of State for Health.<sup>1134</sup>

A new minister brief on the Archer report was prepared for this handover.<sup>1135</sup> The key concerns for interested stakeholders were said to be that the increase in funding for the Macfarlane and Eileen Trusts was too little; that there would be no review of the Skipton Fund until

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1130 Memo from Dr Rowena Jecock to Dawn Primarolo 1 June 2009 pp1-3 DHSC5004646

1131 Email chain between Dr Rowena Jecock, Morven Smith and others dated 1 June 2009 DHSC0041219\_087

1132 Memo from Dr Rowena Jecock to Dawn Primarolo 2 June 2009 p3 DHSC0041219\_077. When asked in evidence about the basis for her understanding of the situation in Ireland, Dr Rowena Jecock could not remember precisely what the source was, but stated that this was the common understanding of her colleagues at the time. Dr Rowena Jecock Transcript 13 July 2022 p86 INQY1000226

1133 Memo from Dr Rowena Jecock to Dawn Primarolo 2 June 2009 p7 DHSC0041219\_077

1134 Written Statement of Baroness Dawn Primarolo paras 3.154-155 WITN5494001

1135 New Minister brief on Lord Archer’s report June 2009 DHSC5575968. Baroness Merron stated in her statement to this Inquiry that she would have received such a briefing but could not remember it. Written Statement of Baroness Gillian Merron para 13 WITN6603001

2014; and that there was “*still no support to those who died before 29 August 2003 who currently cannot claim (an anomaly the widows were campaigning to be rectified)*”[sic].<sup>1136</sup>

In respect of the recommendation for parity with Ireland, the briefing advised that:

*“Lord Archer’s recommendation to mirror the payments to those made by Ireland is a little misleading as the circumstances there were different, but campaigners have nevertheless latched onto these significantly larger sums.*

*The Government here has never accepted any liability. We believe that people were offered the best treatment available at the time and that as soon as blood screening tests were available they were implemented. There were attempts to bring litigation against the Government by those infected with HIV in the early 1990s but these were withdrawn following legal advice to the plaintiffs that they were unlikely to win their case. However as a gesture of goodwill, the Government established the Macfarlane and Eileen Trusts at that time for those infected with HIV – and the Skipton Fund in 2004 for hepatitis C. Payments from all these funds are ex gratia goodwill payments only.*

*In Ireland also, the State did not explicitly admit liability. However, contrary to the position in the UK, the Irish Blood Transfusion Service (IBTS) was found, by a judicial inquiry, to have been responsible on two occasions (1977 and again in 1991) for failures which resulted in the large-scale contamination with hepatitis C of a blood product used to treat pregnant women”*.<sup>1137</sup>

On 10 June 2009 Chris James of the Haemophilia Society wrote a letter to the new Secretary of State, raising the issue of the Government’s response to the Archer report. He expressed the Society’s disappointment and its belief that the action announced did not come “*even close*” to discharging the Government’s moral responsibility. He requested an urgent meeting.<sup>1138</sup> Also on 10 June 2009, Gillian Merron was sent a further briefing from Dr Rowena Jecock and her team which advised that her predecessor had sought information on what might be done sooner to help Skipton Fund beneficiaries, “*but any of these options would be costly and Treasury approval would be needed for any new expenditure above £5m.*”<sup>1139</sup>

The following day, 11 June 2009, Gillian Merron met Liz Woodeson, the director of the Health Protection Division, to discuss the briefing.<sup>1140</sup> There was a subsequent discussion about lines to take in correspondence; the Minister wished to include a sympathetic paragraph in each response extending her sympathy to patients and families who had suffered, but had also expressed the “*desire to stick to the Government line and close down this issue.*”<sup>1141</sup>

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1136 New Minister brief on Lord Archer’s report June 2009 p4 DHSC5575968

1137 New Minister brief on Lord Archer’s report June 2009 p3 DHSC5575968

1138 Letter from Chris James to Andy Burnham 10 June 2009 HSOC0011228\_002

1139 Memo from Dr Rowena Jecock to Gillian Merron 10 June 2009 p4 DHSC5066506

1140 Memo from Dr Rowena Jecock to Gillian Merron 10 June 2009 p1 DHSC5066506

1141 Email chain between Morven Smith and Liz Woodeson 10-11 June 2009 pp2-3 DHSC6456681

On 19 June 2009, Dr Rowena Jecock and her team provided a briefing for the new Secretary of State. This briefing highlighted two aspects of Lord Archer's recommendations. The first was whether the level of financial relief should be based on the much higher level of payments made in Ireland. The briefing advised that in Ireland the Blood Transfusion Service was found to have been at fault, which was "*not the case here.*" The second was the recommendation to include surviving spouses whose partners infected with Hepatitis C died before the Skipton Fund was established, in line with the eligibility criteria for the HIV Trusts. Previous ministers' decisions to make no change to financial relief for Hepatitis C was "*essentially because of affordability*"; the cost estimates were set out.<sup>1142</sup> Andy Burnham gave evidence to this Inquiry that this was an "*incorrect line*", and he thought the starting point ought to have been, "*what's happened to people? What is the impact on their lives? What do they need?*"<sup>1143</sup>

On 3 July 2009, Lord Morris wrote to the Secretary of State at his constituency address, asking Andy Burnham to meet him and Lord Archer to discuss the Government's response to Lord Archer's report "*in keeping with Privy Council terms*", by which he meant "*unannounced and held in strict privacy*". He warned that "*the issue could become an explosive one unless we can make some move now toward closure*".<sup>1144</sup>

## Public statements comparing the UK with Ireland

On 23 June 2009, Gillian Merron answered a topical question in the House of Commons from Dr Brian Iddon MP asking why Lord Archer's recommendation regarding parity between Hepatitis C and HIV sufferers "*as in the Irish Republic and several other countries*" had been rejected.<sup>1145</sup> She replied:

*"I deeply regret that patients have contracted serious infections as a result of NHS treatment 20 or more years ago. However, it is the different circumstances of patients that are reflected in the different financial arrangements. We will review the Skipton fund, which was set up for those infected with hepatitis C, in 2014, 10 years after its commencement. I cannot accept the comparison with Ireland, because the Irish blood transfusion service was found to be at fault, and that was not the case here."*<sup>1146</sup>

On 1 July 2009, there was a Westminster Hall debate on the Archer Inquiry.<sup>1147</sup> During the course of this debate, Dr Brian Iddon asked the Minister about her previous reply, suggesting

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1142 Memo from Dr Rowena Jecock to Andy Burnham 19 June 2009 DHSC5172177

1143 Andy Burnham Transcript 15 July 2022 pp43-44 INQY1000228

1144 Letter from Lord Morris to Andy Burnham 3 July 2009 p2 DHSC0041307\_006

1145 Hansard House of Commons debate on Lord Archer's recommendation 23 June 2009 p2 DHSC0015671

1146 Hansard House of Commons debate on Lord Archer's recommendation 23 June 2009 p2 DHSC0015671

1147 Hansard House of Commons debate on the Archer Inquiry 1 July 2009 DHSC0015672. Morven Smith had requested a briefing pack for the debate by email on 24 June 2009. Email from Morven Smith

that contrary to her stated position “*the Irish paid out without liability and before any tribunal had met to discuss the position.*”<sup>1148</sup> Gillian Merron answered:

*“I stand by the points that I made. Furthermore, a judicial inquiry in Ireland found failures of responsibility by the Irish blood transfusion service and concluded that wrongful acts had been committed. As a result, the Government of the Republic of Ireland decided to make significant payments to those affected ... that was not the case with the blood transfusion service here.”*<sup>1149</sup>

This answer reflected the briefing with which the Minister had been provided.<sup>1150</sup> She was also provided with the draft of a speech, which asserted that before concentrates became available the life expectancy of someone with severe haemophilia was less than 30 years; that although there were warning voices about the risk from infection, “*the consensus both within the scientific and haemophiliac communities was that the risk was low and worth taking*”; and which described the treatment as “*The best available treatment at that time.*” It asserted also that “*If governments, doctors and other experts had known then what we do now, we could have prevented perhaps the greatest tragedy in the history of the NHS. But the fact is, they did not.*”<sup>1151</sup> I do not criticise the Minister herself for these assertions: she was relatively new in post, this was a speech written by officials, and she was dependent on those officials for an accurate and balanced briefing. However, what officials told her to say was partial and misleading. The reference to life expectancy wholly ignored the contribution to life expectancy made by cryoprecipitate.<sup>1152</sup> The reference to a consensus with the haemophilia community glossed over the fact that people cannot agree that a risk is low and worth taking unless they have been individually advised of the risks and benefits: the evidence before this Inquiry overwhelmingly establishes that they were not, and there is no evidence that the Department of Health took steps to inform itself as to the position such that it could properly brief the Minister that this was the case. The repeated line to take about best available treatment was flatly wrong, and is considered elsewhere in this Report. Finally, the suggestion that governments, doctors and other experts did not have the information to take preventive steps was also wrong – as this Report demonstrates – but what is of particular concern in relation to this briefing is that officials felt able to make this confident statement without a proper evidential basis for doing so. They made it so that

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to Dr Rowena Jecock 24 June 2009 WITN6603005. This was provided on 29 June 2009. Email from Mark Noterman to Morven Smith 29 June 2009 DHSC5119404

1148 Hansard House of Commons debate on the Archer Inquiry 1 July 2009 p8 DHSC0015672

1149 Hansard House of Commons debate on the Archer Inquiry 1 July 2009 p8 DHSC0015672

1150 Briefing Pack 29 June 2009 p8 DHSC5119406. It also reflected the draft speech written for her. Email from Mark Noterman to Morven Smith 29 June 2009 p1 DHSC5119404, Draft Speech for Westminster Hall adjournment debate 29 June 2009 pp9-10 DHSC5119405

1151 Draft Speech for Westminster Hall adjournment debate 29 June 2009 DHSC5119405. These assertions were repeated in the Minister’s actual speech in the Westminster Hall debate, save that instead of referring to what “*governments, doctors and other experts*” had not known at the time, she referred just to “*doctors and medical experts*”. Hansard House of Commons debate on the Archer Inquiry 1 July 2009 p5 DHSC0015672

1152 See the chapter on *Treatment of Bleeding Disorders*.

that assertion would be relayed to the public. The public were thus always at risk of being misled, and in the respects identified above, they were.

### Correspondence with members of the public

Meanwhile, members of the public also wrote to the Government regarding the response to the Archer report.<sup>1153</sup> An illustrative example is the letter from Stephen Wintle, whose wife Colette had been infected with Hepatitis B and C, dated 16 June 2009. He wrote to the Secretary of State about their family's consequent financial difficulties, and stated that:

*“Lord Archer’s inquiry has made recommendations that would allow those victims who remain alive, and widows of the deceased to remove the financial hardship they have been battling with for many years, allowing them dignity and the ability to get on with, what is left of their lives. It is for these reasons that Lord Archer recommended compensation on a parity with Erie [sic] as a starting point.”*<sup>1154</sup>

A reply was sent from the Department of Health's Customer Service Centre, reflecting the Department's standard lines<sup>1155</sup> to take on the topic:

*“This Government deeply regrets that patients acquired serious infections as a result of NHS treatment some two or more decades ago, and extends every*

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1153 On 22 May 2009 Gregory Murphy wrote to ministers regarding the Department of Health's “*pitiful response to the Archer Report*”, pointing out that his “*still grieving mother who was 56 when she was widowed and is now 71 and has never received a single penny piece in assistance from the UK government and has been subject to making ends meet since 1994 through loans, re-mortgages and scrimping.*” His father had been infected with Hepatitis C; his father's late brothers with HIV; “*that's three dead haemophiliac brothers, two diseases (or three if you include Hepatitis B which is a dangerous, dangerous condition) and two totally different responses from the Department of Health.*” Gregory Murphy pointed too to the “*entirely arbitrary cut-off point (of August 30th 2003) to recognise the widows of those who were infected with Hepatitis C.*” Email from Gregory Murphy to ministers 22 May 2009 WITN1944385. He received a response from the Department of Health's Customer Service Centre which repeated standard lines, asserted that “*patients received the best available treatment at the time*”, stated that the Government had made “*as positive a response as possible*” to the Archer recommendations and indicated that the Department of Health did not intend to revisit its response. Email from the Department of Health to Gregory Murphy 19 June 2009 WITN1944399.

Carol Grayson wrote to the Secretary of State on 29 June 2009, setting out her concerns “*with regard to misinformation that has been perpetuated by the Department of Health for the last five years relating to the situation of haemophiliacs in Eire and the Irish government/blood transfusion service.*” She referred to evidence submitted to show that compensation was paid in Ireland on compassionate grounds and without any finding of legal liability in the Irish courts. Letter from Carol Grayson to Andy Burnham 29 June 2009 WITN1055142

1154 Letter from Stephen Wintle to Andy Burnham 16 June 2009 WITN1056098. Colette Wintle wrote to the Secretary of State on 29 June 2009 expressing concern about the Government's response to the Archer Report and the Government's repeated reference to the position in Ireland being a result of wrongdoing and findings of liability. Letter from Colette Wintle to Andy Burnham 29 June 2009 WITN1056101. She received a response from the Department of Health's Customer Service Centre which maintained that the compensation scheme in Ireland had been set up in the light of evidence of mistakes by the Blood Transfusion Service Board and distinguished that from the position in the UK. Letter from Mary Heaton to Colette Wintle 29 July 2009 WITN1056107

1155 Reference to this letter containing “*standard lines*” is in an email chain between Department of Health officials dated 16-27 July 2009, which also said that “*I suspect we have not heard the last from Mr or Mrs Wintle. Presumably, if they continue to ask similar questions we ought to tell them that we do not intend reply [sic] to reply to their letters.*” Email chain between Mary Heaton and Edward Goff 16 July 2009 pp1-2 DHSC6696667

*sympathy to the patients and their families who have suffered as a result of the very treatments that should have transformed their lives for the better.*

*The Government understands the sense of grievance that some people may feel as a result of what has happened, and that there are deeply held opinions on the appropriateness and timeliness of decisions and actions taken many years ago. In his report, Lord Archer did not find the government of the day to have been at fault, and did not apportion blame.*

*The Department is committed to ensuring that people with haemophilia, and others who have been infected with hepatitis C and/or HIV from blood and blood products, are well cared for, supported in their communities and fully informed about how best to look after their health. The Department gave very careful consideration to Lord Archer's recommendations to see what more it could do, and has made as positive a response as possible."*<sup>1156</sup>

Andy Burnham's evidence to this Inquiry was that he would not personally have had sight of correspondence of this kind with a member of the public. On reading the response in the course of preparing his evidence, he (rightly) considered it was incorrect to say that the Government had made "*as positive a response as possible*" to Lord Archer's recommendations.<sup>1157</sup> He further stated that while it was not the fault of the individual correspondent in the Department of Health, the approach of replying with prepared standard lines was "*defensive*" and "*stonewalling*", reflecting an overarching "*financial exposure concern, which is fundamentally the wrong way in which to address an issue that has caused such devastation to British families.*"<sup>1158</sup>

On 19 June 2009, a protest took place outside Andy Burnham's constituency office in Leigh, which increased his awareness of the issue soon after taking up his new role.<sup>1159</sup> He later replied personally to a letter from David Tonkin, chair of the Manor House Group, which had been handed to him at or after the protest.<sup>1160</sup>

### **The Andrew March judicial review**

Campaigner Andrew March issued judicial review proceedings in respect of the Government's response to the Archer Inquiry on 20 August 2009.<sup>1161</sup> In particular, he

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1156 Letter from Paul Larkin to Stephen Wintle 22 June 2009, WITN1056099. A reply to this letter dated 29 June 2009 is at WITN1056100: it unsurprisingly (and correctly) points out that the Department of Health reply did not answer his questions. Letter from Stephen Wintle to Andy Burnham 29 June 2009 WITN1056100

1157 Andy Burnham Transcript 15 July 2022 pp50-52 INQY1000228

1158 Andy Burnham Transcript 15 July 2022 pp57-58 INQY1000228

1159 Written Statement of Andy Burnham paras 10.7-10.10 WITN7060001, Written Statement of David Tonkin para 89 WITN1567008

1160 Letter from Andy Burnham to David Tonkin 16 July 2009 PMOS0000191. In evidence, Andy Burnham said he no longer believed that it was correct to say, as he had in this letter, that there was "*no evidence that individuals were knowingly infected.*" Andy Burnham Transcript 15 July 2022 p63 INQY1000228

1161 *R (March) v Secretary of State for Health* 16 April 2010 para 7 DHSC0003819\_011

challenged the Government's reasoning for failing to adopt Lord Archer's recommendation 6(h), that "*payments should be at least the equivalent of those payable under the scheme which applies at any time in Ireland.*" He argued that Gillian Merron's responses to Dr Brian Iddon, first in reply to his oral question on 23 April 2009 and second in the debate in Westminster Hall on 1 July 2009, revealed that the Government's reasoning was based on a material error of fact as to the situation in Ireland.<sup>1162</sup> He contended that contrary to the Minister's statements, the Irish Government decided to make payments at a full, compensatory level for compassionate reasons before, and therefore not because of, any finding of fault had been made.<sup>1163</sup>

Andrew March had written to the Department of Health on 5 June 2009, stating that he was unhappy with the proposed level of payments from the Macfarlane Trust. He wrote:

*"This proposal is diametrically opposed to the regaining of financial independence for beneficiaries described in the Archer Report. The proposal misses entirely the essence of Recommendation 6, where it is stated that payments should be at least the equivalent of those payable under the Scheme which applies at any time in Ireland ... My campaigning for full equality with Ireland ... will continue"*.<sup>1164</sup>

He received a letter in response which reflected the Department's standard lines. In relation to the question of parity with Ireland, the reply stated:

*"You refer to Lord Archer's recommendation that payments should be at least the equivalent of those under the scheme which applies at any time in the Republic of Ireland. Payments made by the Republic of Ireland are a matter for that country and were introduced following a judicial inquiry which found failures of responsibility by the Irish Blood Transfusion Service and concluded that wrongful acts were committed.*

*The situation in the UK was different. Action was taken in 1985 to introduce heat treatment, which removed the risk of both HIV and of hepatitis C from blood products. Testing of all donations for HIV was introduced in 1985, and for hepatitis C in 1991 when suitable, effective tests became available. The establishment of the ex-gratia payment schemes in the UK was in recognition of the special and unfortunate position of those who were infected."*<sup>1165</sup>

Deborah Webb, working in the Health Protection Division, provided a written statement in response to the judicial review claim on behalf of the defendant Secretary of State for Health.<sup>1166</sup> She said the rough initial costing for replicating in the UK a scheme with equivalent

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1162 *R (March) v Secretary of State for Health* 16 April 2010 para 19 DHSC0003819\_011

1163 *R (March) v Secretary of State for Health* 16 April 2010 para 21 DHSC0003819\_011

1164 Letter from Andrew March to William Connon 5 June 2009 ARCH0000468

1165 Letter from Dora East to Andrew March 24 June 2009 PMOS0000192

1166 Witness Statement of Deborah Webb in *R (March) v Secretary of State for Health* 16 February 2010 DHSC0015684. Deborah Webb reported to Dr Rowena Jecock. Written Statement of Deborah Webb paras 2.11-2.12 WITN7409001



compensation to Ireland was £3-3.5 billion.<sup>1167</sup> This referred to the very first briefing by Dr Rowena Jecock on 24 February 2009, referred to above.

### Further internal discussions in the Department of Health in 2009

On 28 August 2009, Deborah Webb provided a briefing to the Secretary of State in advance of a planned meeting with Gillian Merron and Baroness Thornton (Parliamentary Under-Secretary of State for Health in the Lords) to discuss the Government’s response to Lord Archer’s report.<sup>1168</sup> Officials advised that the Ministers should maintain the position set out in the Government’s response published on 20 May 2009. It was noted that:

*“This is a sensitive issue, which although it has not received a high level of media coverage, has support from parliamentarians in both the Commons (especially Jenny Willott, secretary to the APPG on haemophilia), and the Lords (especially Lord Morris, President of the Haemophilia Society). It is likely that you will be lobbied about the Government’s response, which is viewed as inadequate by those affected by HIV/hepatitis C and their supporters. In addition, we have also received notice of an application for a judicial review of the Government’s response to Lord Archer’s recommendation on financial relief for those affected.”*<sup>1169</sup>

The main areas of criticism were identified to be:

- *“Although we are increasing the payments for those affected by HIV from an overall average of £6,400 a year to a flat rate of £12,800 per annum for those infected, this was considered to be nowhere near enough (Lord Archer described it as “tossing a bone to a dog”)*
- *That we should be increasing payments now to hepatitis C patients and their dependents [sic] — rather than just promising to review the Skipton Fund in five years time (ten years after its establishment).*
- *The level of payments should be closer to the amounts paid in Ireland which are claimed to be an average of £1m per person (for both HIV and hepatitis C sufferers) and up to £5m per person in some cases.”*<sup>1170</sup>

Lord Archer’s recommendation to increase payments to a level reflective of those paid in Ireland was said to be *“misleading as the circumstances there were different, but campaigners have nevertheless latched onto these significantly larger sums”*; it was recognised that the state in Ireland had not explicitly admitted liability but repeated that the Irish Blood Transfusion Service had been found by a judicial inquiry to have been responsible for

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1167 Witness Statement of Deborah Webb in *R (March) v Secretary of State for Health* 16 February 2010 para 59 DHSC0015684

1168 Memo from Deborah Webb to Andy Burnham 28 August 2009 DHSC0041307\_002

1169 Memo from Deborah Webb to Andy Burnham 28 August 2009 p1 DHSC0041307\_002

1170 Memo from Deborah Webb to Andy Burnham 28 August 2009 p3 DHSC0041307\_002

failures which resulted in a blood product used to treat pregnant women being contaminated with Hepatitis C.<sup>1171</sup>

The three ministers met on 10 September 2009. A summary of the meeting shows that they were “*keen for some work to be done on the smaller points we can address*” such as improving benefits forms in liaison with the Department for Working and Pensions.<sup>1172</sup> The record went on:

*“Generally, speaking Ministers wanted the Department to be more on the front foot and take credit for the things the Government had done in this area (eg the setting up of the Skipton Fund in the first place). They wanted better handling plans, putting out positive messages/finding good new [sic] stories to announce on this issue, rather than being passive and defensive.”*<sup>1173</sup>

Andy Burnham’s evidence to this Inquiry was that at this time the ministers were “*beginning the process of saying to the Department, ‘This can’t stay where it is’*” and querying the line agreed by the previous ministers, but that officials were reluctant to reopen the issue.<sup>1174</sup>

### **Dialogue between ministers and politicians campaigning on infected blood issues**

Gillian Merron attended a meeting with Lord Archer and cross-party MPs (Jenny Willott, Alistair Burt and Dr Brian Iddon) regarding the Government’s response to the Archer report on 21 October 2009, at which the level of payments, proposed date for review of the Skipton Fund, and the issue of parity with Ireland were discussed.<sup>1175</sup>

Andy Burnham met informally with Lord Morris in or around September 2009, which he says compounded his feeling that the issue could not be left as decided by previous ministers.<sup>1176</sup> He also met with Paul Goggins, Dr Brian Iddon and affected haemophilia patients and their families in January 2010,<sup>1177</sup> which he describes as having had a profound impact on him.<sup>1178</sup>

Lord Morris laid a Private Members’ Bill, the Contaminated Blood (Support for Infected and Bereaved Persons) Bill, in the House of Lords on 19 November 2009.<sup>1179</sup> The Bill had its Second Reading in the Lords on 11 December 2009. During the course of the debate, Lord Morris challenged the Government’s previous statements to the effect that the level of

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1171 Memo from Deborah Webb to Andy Burnham 28 August 2009 pp3-4 DHSC0041307\_002

1172 Email from Yemi Fagun to Deborah Webb and others 11 September 2009 p3 DHSC5803265

1173 Email from Yemi Fagun to Deborah Webb and others 11 September 2009 p4 DHSC5803265

1174 Andy Burnham Transcript 15 July 2022 pp81-82 INQY1000228

1175 Minutes of Lord Archer meeting 21 October 2009 HSOC0011278. Baroness Merron raised a query about the accuracy of this minute in her statement. Written Statement of Baroness Gillian Merron para 33 WITN6603001

1176 Written Statement of Andy Burnham paras 10.17-10.20 WITN7060001

1177 Memo from Deborah Webb to Yemi Fagun and others 14 December 2009 DHSC5190274. The briefing advised the Secretary of State to hold the previously published lines; his evidence was that officials did not encourage him to take this meeting. Andy Burnham Transcript 15 July 2022 p86 INQY1000228

1178 Andy Burnham Transcript 15 July 2022 pp89-94 INQY1000228

1179 Memo from Dr Rowena Jecock to Clare MacDonald and others 25 November 2009 DHSC0041240\_016

compensatory payments in Ireland was responsive to a finding of fault. Baroness Thornton responded that “*the situation [in Ireland] is quite different from the situation here in the UK.*”<sup>1180</sup>

On 5 January 2010, Baroness Thornton provided a written answer in response to a follow-up parliamentary question from Lord Morris, in which she reiterated that “*The compensation scheme in the Republic of Ireland was set up in light of evidence of mistakes by the Irish Blood Transfusion Service Board.*”<sup>1181</sup>

Lord Morris’ Bill passed through the House of Lords on 21 January 2010 and had its first reading in the Commons on the same day, sponsored by Edward O’Hara. On 23 February 2010, Gillian Merron wrote to Lord Morris and Edward O’Hara inviting them to meet.<sup>1182</sup> The response on behalf of Lord Morris invited the Minister to correct the parliamentary record vis-à-vis her statement to the House of Commons on 1 July 2009 distinguishing the situation in the UK from that in Ireland.<sup>1183</sup> This elicited a holding response, together with a renewed invitation to meet.<sup>1184</sup>

The Minister did meet with Lord Morris on 11 March 2010.<sup>1185</sup> She also met with Edward O’Hara, together with Sylvia Heal MP, on or shortly before 12 March 2010.<sup>1186</sup> The question of comparability with Ireland was raised again at this meeting.<sup>1187</sup> Following the meeting, the Minister requested “*a definitive explanation of the Irish position*”, with a view to providing a briefing note for MPs.<sup>1188</sup>

### Bringing forward the review of the Skipton Fund

In or around late January 2010, the Secretary of State held a meeting with Gillian Merron, the Permanent Secretary Hugh Taylor, and other senior officials in the Department of Health to discuss contaminated blood issues during which, among other matters, he pushed for the planned review of the Skipton Fund to be brought forward from 2014.<sup>1189</sup> Following this meeting, or perhaps a similar discussion around the same time, Gillian Merron’s Assistant

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1180 Hansard written answer on Contaminated Blood Bill 11 December 2009 p25 HSOC0017172

1181 Hansard written answer on Contaminated Blood 7 January 2010 p2 WITN6603010

1182 Letters from Gillian Merron to Edward O’Hara 23 February 2010 WITN6603011

1183 Letter from Judy Phillips to Gillian Merron 3 March 2010 DHSC0004118\_026

1184 Letter from Yemi Fagun to Lord Morris 9 March 2010 WITN6603012. A substantive response was later delayed pending the outcome (including any appeal decision) in Andrew March’s judicial review. See Written Statement of Baroness Gillian Merron paras 47-52 WITN6603001

1185 An email from Yemi Fagun to Gillian Merron refers to this earlier meeting. Email from Yemi Fagun to Gillian Merron 12 April 2010 p8 WITN6603014. Baroness Merron considers it likely she did meet with him on this date although she cannot now remember the meeting. Written Statement of Baroness Gillian Merron para 45 WITN6603001

1186 On which date Yemi Fagun wrote an email to Dr Rowena Jecock containing a summary of the meeting. Email from Yemi Fagun to Dr Rowena Jecock 12 March 2010 pp4-5 WITN6603013

1187 Email from Yemi Fagun to Dr Rowena Jecock 12 March 2010 p4 WITN6603013

1188 Email from Dr Rowena Jecock to Benjamin Cole 17 March 2010 p2 WITN6603013. Subsequently, in the same email chain, advice was given that any briefing should wait until after the outcome of Andrew March’s judicial review. Email from Kent Graham to Dr Rowena Jecock and others 17 March 2010 p2 WITN6603013

1189 Written Statement of Andy Burnham paras 10.29-10.32 WITN7060001

Private Secretary asked Dr Rowena Jecock to provide options for bringing forward the review of the Skipton Fund.<sup>1190</sup>

This resulted in a briefing paper from Dr Rowena Jecock and her team dated 3 March 2010, which advised against bringing the review forward on the basis that the Department of Health was already over-committed on funding for 2010-2011. The risks of taking this approach were emphasised. An alternative option, of providing access to personal health budgets, without providing extra money to those affected, was suggested instead. The note concluded, *“If you wish us to identify funding for this, then cuts will be required in other priority programmes.”*<sup>1191</sup>

Despite this discouraging briefing, Gillian Merron requested further advice on options to bring forward a review of the Skipton Fund, as well as more detail on the possibility of personalised budgets for people with haemophilia. This request was met with a briefing authored by Deborah Webb, which did outline three alternative options. These were: bringing forward a full review, undertaking a review subject to pre-identified finite non-recurrent funding, or addressing anomalies in the scheme without a formal review. However, officials again strongly advised holding the existing line.<sup>1192</sup>

The Minister’s Private Office replied saying that, *“SofS [Secretary of State ] and MS(PH) are keen to take this forward and has asked for a meeting as soon as it can be arranged.”*<sup>1193</sup> This meeting, between the Secretary of State, the Minister, Dr Rowena Jecock and Deborah Webb took place on 24 March 2009. The Secretary of State’s Assistant Private Secretary sent a follow-up email confirming that the Ministers’ clear preference was to bring forward a full review of the Skipton Fund.<sup>1194</sup> Gillian Merron subsequently agreed this plan with Nicola Sturgeon, then Deputy First Minister of Scotland and Edwina Hart, Minister for Health in Wales.<sup>1195</sup>

On 6 April 2010, the Minister issued a written ministerial statement bringing forward the review of the Skipton Fund to *“as soon as possible this year.”* The statement read:

*“Further to the Government’s response to Lord Archer of Sandwell’s report on NHS-supplied contaminated blood and blood products, which we published on 20 May 2009, I wish to inform the House that we have decided to bring forward*

1190 Email from Yemi Fagun to Dr Rowena Jecock and others 24 February 2010 pp2-3 DHSC6482184

1191 Memo from Dr Rowena Jecock to Yemi Fagun 3 March 2010 pp3-4 DHSC0041307\_015

1192 Memo from Deborah Webb to Yemi Fagun 17 March 2010 pp1-2 DHSC0041307\_014. The relevant paragraph said: *“Due to the complexity of this review, the potential legal repercussions and the far reaching complications for other Government Departments, we strongly advise not to rush any review – especially having decided so far to maintain the existing position. There will be many legal and policy requirements we will have to address and we think it is highly risky to promise something in a hurried way now that may prove to be difficult, or not possible, to achieve. We also run the risk of exposing the Department to further legal challenge by way of Judicial Reviews.”*

1193 Email from Yemi Fagun to Deborah Webb and others 22 March 2009 pp6-7 DHSC5616528

1194 Email from Clare MacDonald to Dr Rowena Jecock and others 25 March 2009 p4 DHSC5616528

1195 Emails from Sarah Kirby to Dr Rowena Jecock and others 25 and 26 March 2009 pp1-3 DHSC5616528

*a review of the Skipton Fund, which makes ex-gratia payments to those infected with hepatitis C as a result of their treatment.*

*The unintended and tragic consequences of these treatments have seriously impaired the lives of many people, together with those of their families. We have listened carefully to the views of those infected, their families, carers and many in this House, who have told us that our intended review date of 2014 will be too late for many of those affected. Consequently, we have decided that the review will begin as soon as possible this year.*

*It will be an independently chaired review. The terms of reference, membership and conduct of the review will be agreed in conjunction with the Devolved Administrations.*

*I would also like to take this opportunity to confirm payment of £100,000 to the Haemophilia Society, as promised in our response of 20 May 2009.*

*I would like to reiterate this Government's sympathy for those affected by these treatments many years ago, before screening tests and methods of viral inactivation became available. We remain fully committed to supporting them in the best way we can."*<sup>1196</sup>

The General Election was called on the same day and Parliament was dissolved on 12 April 2010.

### **Outcome of the Andrew March judicial review**

The judgment in the judicial review claim was handed down by Mr Justice Holman on 16 April 2010.<sup>1197</sup> The judge found that the Irish scheme: was fully compensatory in design; was *ex gratia* in nature; had existed on a non-statutory footing prior to the Finlay Report; and was not limited to women infected through anti-D (investigated by the Finlay Tribunal).<sup>1198</sup> He therefore concluded that the Government's approach to Lord Archer's recommendation 6(h) had been "*infected by an error*",<sup>1199</sup> and the claim for judicial review succeeded. Recognising the limitations of judicial review, he also observed that: "*the allocation of resources is entirely a matter for the government. They have said, in effect, that they cannot afford to pay more; and that is entirely a matter for them, as to which I neither express, nor have, any opinion or comment whatsoever.*"<sup>1200</sup>

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1196 Written Ministerial Statement on Contaminated Blood: Review of the Skipton Fund 6 April 2010 ARCH0001105. Advice to make the announcement by way of a written ministerial statement was given by Dr Rowena Jecock. Memo from Dr Rowena Jecock to Sarah Kirby 26 March 2010 p1 DHSC0041307\_017

1197 *R (March) v Secretary of State for Health* 16 April 2010 DHSC0003819\_011

1198 *R (March) v Secretary of State for Health* 16 April 2010 para 41 DHSC0003819\_011

1199 *R (March) v Secretary of State for Health* 16 April 2010 para 53 DHSC0003819\_011

1200 *R (March) v Secretary of State for Health* 16 April 2010 para 50 DHSC0003819\_011

A briefing was provided to the Secretary of State on 15 April 2010, advising that leave to appeal should be sought.<sup>1201</sup>

## Change of ministerial team following the May 2010 General Election

On 6 May 2010, the General Election took place, resulting in the formation of the Coalition Government. The new Secretary of State for Health was Andrew Lansley. Anne Milton became Parliamentary Under-Secretary of State for Public Health, with responsibility for blood and blood products.

On 26 May 2010, a briefing note was provided to Anne Milton recommending that the Government should not appeal Mr Justice Holman's decision.<sup>1202</sup> This would entail reconsideration of Lord Archer's recommendation 6(h) for parity of compensation with Ireland, with a new decision being taken. Anne Milton agreed with that approach.<sup>1203</sup>

On 4 June 2010, Deborah Webb provided a further briefing.<sup>1204</sup> This advised the Parliamentary Under-Secretary of State to oppose Lord Morris' Contaminated Blood Bill, which he had reintroduced since the General Election.

### Re-making of the decision on Lord Archer's recommendation 6(h)

On 8 July 2010, Deborah Webb sent Anne Milton a submission on how to approach making a new decision in respect of Lord Archer's recommendation 6(h) for parity of compensation with Ireland.<sup>1205</sup> She noted that the Minister was due to meet with campaigners and hear their evidence on 15, 20 and 22 July 2010, and that a final decision should be made after that. However, the recommendation was made at that point – even before these meetings had taken place – to reject the recommendation “*on the basis that it is unmeritorious, on grounds of both: (i) the factual difference between Rol & UK; and (ii) affordability.*”<sup>1206</sup> In respect of the first, the findings of the Finlay Tribunal in Ireland were again relied upon as a relevant distinguishing factor, notwithstanding the outcome of the judicial review claim. In respect of the second, the rough initial costing of £3-3.5 billion to achieve parity was said to be “*an underestimate.*”<sup>1207</sup> An international comparison of contaminated blood compensation schemes was provided in an annex to the briefing.<sup>1208</sup> The briefing also suggested that the Minister should reconsider the previously announced decision to bring forward the review of

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1201 Memo from Deborah Webb to Clare MacDonald 15 April 2010 DHSC5081242

1202 Memo from Deborah Webb to Yemi Fagun 26 May 2010 DHSC0003623\_004

1203 Email from Giancarlo Laura to Benjamin Cole and others 2 June 2010 p2 DHSC6512976

1204 Memo from Deborah Webb to Yemi Fagun 4 June 2010 DHSC5032774

1205 Memo from Deborah Webb to Yemi Fagun 8 July 2010 DHSC0006616\_114

1206 Memo from Deborah Webb to Yemi Fagun 8 July 2010 p2 DHSC0006616\_114

1207 Memo from Deborah Webb to Yemi Fagun 8 July 2010 p4 DHSC0006616\_114

1208 Annex Contaminated Blood – International Compensation Schemes DHSC0006616\_008

the Skipton Fund; as the review had not yet commenced, the Minister could decide whether it should proceed.<sup>1209</sup>

Anne Milton held meetings with campaigners and other interested parties, as referred to in the briefing, including representatives from the Haemophilia Society, the Hepatitis C Trust, Tainted Blood, the Manor House Campaign and the Contaminated Blood Coalition.<sup>1210</sup> Christopher FitzGerald, chairman of the Macfarlane Trust, had written to her soon after her appointment, urging her to consider increasing funding to the Trust.<sup>1211</sup> She met Christopher FitzGerald, together with Peter Stevens, chair of the Eileen Trust and the Skipton Fund, on 15 July 2010.<sup>1212</sup> On 22 July 2010, the Minister met Colette Wintle, who had been infected with Hepatitis B and C in the course of treatment for haemophilia,<sup>1213</sup> and Carol Grayson, who had lost her husband, Pete Longstaff, as a result of his exposure to contaminated blood products.<sup>1214</sup> They spoke of their personal experiences and their research and campaign work.<sup>1215</sup>

On 11 August 2010, Deborah Webb provided an updated version of her previous submission. The advice remained that Lord Archer’s recommendation regarding parity with Ireland should be rejected; officials now also recommended that the review of the Skipton Fund should be put on hold while the Minister considered evidence from the July meetings with campaigners.<sup>1216</sup> Anne Milton’s response was that she wanted to make only one announcement on contaminated blood, did not want to say anything about recommendation 6(h) until all the other issues had been resolved, and wanted solid legal advice on how to achieve this and “*still stay on the right side of the law.*” She also wanted exploration of the possibility of reviewing the Skipton Fund at a lower cost.<sup>1217</sup>

On 6 September 2010, Benjamin Cole provided a follow-up submission continuing to recommend that an announcement should be made rejecting Lord Archer’s recommendation 6(h), but at the same time, a review of wider issues (not limited to the question of a Skipton Fund review) should be instigated.<sup>1218</sup> A further submission on 16 September 2010 noted

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1209 Memo from Deborah Webb to Yemi Fagun 8 July 2010 p6 DHSC0006616\_114

1210 Written Statement of Anne Milton para 4.12 WITN6437002

1211 Letter from Christopher FitzGerald to Anne Milton 24 May 2010 DHSC6694804

1212 Brief for meeting with Christopher FitzGerald and Peter Stevens 15 July 2010 WITN6437005. At the meeting, the two chairs argued that the post-Archer increases to payments ought to have been greater. Email from Yemi Fagun to Deborah Webb and others 15 July 2010 DHSC6699991

1213 Written Statement of Colette Wintle WITN1056001

1214 Written Statement of Carol Grayson WITN1055001

1215 Minutes of Department of Health meeting 22 July 2010 WITN1055150

1216 Memo from Deborah Webb to Yemi Fagun 11 August 2010 DHSC0006649

1217 Email from Yemi Fagun to Deborah Webb 16 August 2010 p4 WITN6437007

1218 Benjamin Cole was a policy manager within the Infectious Diseases and Blood Policy branch of the Department of Health. Memo from Benjamin Cole to Yemi Fagun 6 September 2010 DHSC0003623\_109. “*SofS and PS(PH) have seen the submission and are minded to go with [the recommended] Option 2 (internal review with appropriate external input). However, SofS has queried the reference to a review of benefits and whether we have DWP agreement to do this.*” Email from Yemi Fagun to Benjamin Cole 9 September 2010 p2 WITN6437007

that Anne Milton had agreed to undertake this review, and provided preliminary costings of the main options the review would be considering.<sup>1219</sup>

On 30 September 2010, Andrew Lansley wrote formally to the Deputy Prime Minister, Nick Clegg, seeking Home Affairs Committee clearance to publish a written ministerial statement rejecting Lord Archer’s recommendation 6(h).<sup>1220</sup> His stated reasons were twofold. The first was the distinction between the UK and the “*very specific events and failings that occurred in Ireland that were unique to that country*”, which he contrasted with there having “*never been any findings of fault here in the UK*”. The second was the estimated in excess of £3 billion financial cost. He wrote that “*a financial commitment of that size would require significant reprioritisation of other essential programmes.*”<sup>1221</sup>

The reason for there not having been “*any findings of fault here in the UK*” was, of course, because successive governments had refused to establish a public inquiry, and had settled litigation.

More details about the proposed terms of reference and conduct of the proposed review into other matters were contained in a submission from Dr Rowena Jecock dated 7 October 2010.<sup>1222</sup> The review was to cover England only and focus on identified anomalies in financial relief afforded to those infected with Hepatitis C in comparison to those infected with HIV; the level of payments under the HIV Trusts would not be revisited.<sup>1223</sup> Approval having been granted by the Home Affairs Committee,<sup>1224</sup> on 14 October 2010, Anne Milton published a written ministerial statement:

*“Having carefully compared the circumstances pertaining here and in the Republic of Ireland during the period when most of the infections occurred, and having taken account of the fact that this tragedy similarly affected many other countries; I do not consider there is a case for accepting Lord Archer’s recommendation 6(h) that levels of payment here should match those made in Ireland. Every country must make its own decisions on financial support for those affected, taking account of its own particular circumstances, and affordability. The scheme in Ireland was set up on that basis, and has not been replicated in any other country, as far as we know. However, our ex-gratia payment schemes for HIV compare well with those of other countries.*

*In addition, it is estimated that implementing a similar scheme to Ireland’s here in the UK, would cost in excess of £3 billion.”*<sup>1225</sup>

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1219 Memo from Benjamin Cole to Yemi Fagun 16 September 2010 DHSC0003814\_049

1220 Letter from Andrew Lansley to Nick Clegg 30 September 2010 DHSC6547137

1221 Letter from Andrew Lansley to Nick Clegg 30 September 2010 p3 DHSC6547137

1222 Email from Marsha David to Yemi Fagun 7 October 2010 DHSC0003623\_062

1223 Email from Marsha David to Yemi Fagun 7 October 2010 p2 DHSC0003623\_062

1224 Written Statement of Lord Andrew Lansley para 18.6 WITN6884001

1225 Written Ministerial Statement by the Department of Health 14 October 2010 DHSC0006626



## Review of support available to those infected and their dependents

The review was undertaken with detailed options presented to Anne Milton by a submission dated 7 December 2010,<sup>1226</sup> and a report produced in January 2011.<sup>1227</sup> This resulted in some additional measures being announced on 10 January 2011 by the Secretary of State: an increase in stage 2 Skipton Fund payments (from £25,000 to £50,000), an annual payment of £12,800 for those infected with Hepatitis C who reached stage 2 (the same amount paid to those infected with HIV), and the establishment of what became the Caxton Foundation.<sup>1228</sup>

## Commentary

The conclusions of the Archer Inquiry – that a full public inquiry should have been held much earlier to address the concerns of the haemophilia community;<sup>1229</sup> that there had been “*procrastination in achieving national self-sufficiency to avoid the use of high-risk blood products from overseas*”; and that “*Commercial priorities should never again override the interests of public health*” – were justified.<sup>1230</sup>

The response of the Department of Health had been to avoid endorsing the Archer Inquiry. Though it provided documents this did not amount to an unfettered access to the Departmental files. It did not facilitate the appearance of witnesses. It did not waive legal professional privilege. The Archer Inquiry lacked the powers available to a statutory inquiry, or the resources necessary to conduct a full investigation. As a result its conclusions were always likely to fall short of a full picture of what had happened, and why.

The Department of Health did however consider the recommendations which the Archer Inquiry was able to make, and they had some influence on what then happened.

For perhaps the first time a distance began to be drawn between the repeated assertion that the best available treatment had been provided and the current Government: thus Morven Smith recorded that the Government **at the time (1980s)** did not accept that there was a case to be answered and did not accept blame; she herself reported that the reasons why government had taken that approach were now unknown.<sup>1231</sup> It also appears to have marked something of a turning point in that Dawn Primarolo started to ask questions about what had happened, and then persisted in this; and it led to Dr Rowena Jecock reporting that “*official documents*” showed problems at various times in achieving self-sufficiency.<sup>1232</sup>

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1226 Memo from Dr Rowena Jecock to Bill Morgan 7 December 2010 DHSC0003814\_090

1227 Review of the support available to individuals infected with Hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants PRSE0004024

1228 Ministerial Statement by Andrew Lansley 10 January 2011 DHSC5205794, Letter from Anne Milton to David Cameron DHSC6700330

1229 As set out in the chapter on *Delay in Holding a Public Inquiry* there should have been a public inquiry much earlier to examine not only the concerns of people with bleeding disorders, but of all those infected through blood and blood products.

1230 The fourth conclusion was about the doctor-patient relationship which I would express as the centrality of the patient when difficult clinical decisions come to be made.

1231 Memo from Dr Rowena Jecock to Dawn Primarolo 24 February 2009 p3 WITN5494033

1232 Submission from Dr Rowena Jecock to Dawn Primarolo 26 February 2009 p1 DHSC0011467

There seems to have been a shift away from a blunt refusal to accept that any wrong had been done to at least contemplating that some might have been.<sup>1233</sup>

However, the analogy Sir John Major used in evidence – that sometimes changing government policy was akin to the time it takes for a great tanker to turn around<sup>1234</sup> – is demonstrable too. Thus, repeatedly, officials assert that there was no proper comparison with Ireland because the government there had accepted blame, and had been found at fault. They had been told this was not so, yet it took a further court case (of judicial review) to confirm it.<sup>1235</sup> Linked to the Irish issue was a reluctance to accept the financial recommendations the Archer Inquiry made.

The officials in the Health Protection Division were concerned about resource issues, which was to an extent understandable in the context of the financial climate at the time.<sup>1236</sup> However, this meant that they looked for reasons to reject Lord Archer’s recommendations rather than regarding the needs of the recipients of infected blood and blood products and their families as the starting point.

This approach made it more difficult for ministers to understand and assess the merits of the recommendations, and to balance financial resource with other relevant factors.

The timing of the June 2009 reshuffle and May 2010 election meant that new ministerial teams came into post. Each was unfamiliar with the nuances of the issues and highly dependent on officials’ advice, especially at the start of their tenure. The Department of Health stuck rigidly to its lines to take. In the case of its line on parity with Ireland, this led to decision-making that was found to be unlawful. A retaken decision largely relied on the same erroneous position.

Although the belief that nothing wrong had been done, that there was no fault, and that the best available treatment was given was waning it was nonetheless proving hard to shake off. Its influence is clear in the Department of Health’s response to the Archer Inquiry and in its persistent belief in the difference between the UK and Ireland.

Though the Archer Inquiry had begun to change the perception of many politicians, and the government was to respond within a further seven years with recognition that wrong may have been done, then that it had been, and to accept that there should be a public inquiry – and finally in 2022 to recognise at least a moral case for compensation – the response to the Archer Inquiry was too concerned with the financial consequences that

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1233 There was evidence of a marked reluctance of civil servants to abandon faith in the previous approach, that no wrong had been done and the best available treatment had been given; Andy Burnham said that officials were reluctant to reopen the issue. Andy Burnham Transcript 15 July 2022 pp81-82 INQY1000228. See also Email from Yemi Fagun to Deborah Webb and others 11 September 2009 p4 DHSC5803265

1234 Written Statement of Sir John Major para 3.52 WITN5284001

1235 *R (March) v Secretary of State for Health* 16 April 2010 DHSC0003819\_011

1236 This concern was shared by ministers: see Baroness Primarolo’s reference to “*financial turbulence and consequential economic stringencies*” and Alan Johnson’s reference to “*an exceptionally difficult economic climate*” after the 2008 financial crisis. Written Statement of Baroness Dawn Primarolo para 5.7 WITN5494001, Written Statement of Alan Johnson para 3.1 WITN7197001

might follow. The events highlight how civil servants repeatedly took care to steer ministers away from anything that might involve expenditure, or be an implicit acceptance of fault. If there had been such an acceptance, expenditure would be bound to follow. They also show how long it may take for government to take a fresh look at evidence to see if the facts do indeed support some of its views, or to look again at practices hallowed by their repetition repeatedly over years.

It is disappointing that government missed an opportunity for reflection, and for challenging its internal beliefs and lines.

What is, however, most disappointing about the response to the Archer Inquiry is the sense it leaves that government was looking to see what was the least that was required of it.

## 6.9 Caxton Foundation

This chapter describes the establishment of the Caxton Foundation, the function of which was to provide discretionary payments to those who had received Stage 1 payments from the Skipton Fund. It examines why the Foundation served only a small proportion of those entitled and looks at reasons for delays and shortcomings in processing payments.

### Key Dates

**March 2011** Caxton Foundation is established by a deed of Trust.

**October 2012** Caxton's National Welfare Committee reports that in the first six months of active operation a third of applications were left undecided because more information was needed.

**March 2013** Ann Lloyd and Jan Barlow express concerns about Caxton's administrative processes, its staff and the communication with beneficiaries.

**February 2014** the Department of Health rejects the business case submitted by Caxton for funding for 2014/15.

**December 2014** Caxton newsletter provides very limited information in terms of guidelines or support for which beneficiaries can apply.

**2014** the Skipton Fund contacts people who have received a Skipton Stage 1 payment, but with whom there has been no subsequent communication. The number of Caxton beneficiaries rises by nearly 60%.

**2014/15** the pressure on funds is such that the annual fuel allowance is reduced.

**January 2015** APPG Report is critical of the Caxton Foundation.

### People

**Jan Barlow** chief executive (from 2013)

**Martin Harvey** chief executive (until 2012)

**Charles Lister** director and vice chair (2011 - 2015)

**Ann Lloyd** chair (2013 - 2015)

**Christopher Pond** chair (2015 - 2018)

**Peter Stevens** chair (2011 - 2013)

### Abbreviations

**APPG** All-Party Parliamentary Group

**NWC** National Welfare Committee, Caxton Foundation

People who contracted Hepatitis C from NHS treatment were entitled to set payments from the Skipton Fund, but not to further one-off payments to meet particular needs as and when they arose. The Archer Inquiry gave focus to the considerable difficulties this could cause. Partly in response to its report in 2009, the Government decided to set up a scheme providing for such grants in the case of need.<sup>1237</sup>

This was achieved by a Trust deed of 28 March 2011 establishing a charity, for which the first trustees were to be Peter Stevens, Roger Evans, and Charles Gore.<sup>1238</sup> Its purpose was to “provide financial assistance and other benefits to meet any charitable need” of individuals who had received a Stage 1 payment from the Skipton Fund, with the exception of those who were beneficiaries of the Macfarlane Trust or the Eileen Trust, and those who received infected blood, blood products or tissue from the NHS but outside England.<sup>1239</sup> In addition to these “primary beneficiaries”, the partners, parents, carers, children and dependants of primary beneficiaries, living or deceased, were also entitled to be considered, irrespective of the date of death. The trustees had the power, with the consent of the Secretary of State for Health, to add to the class of primary beneficiaries those who had received the relevant treatment in Scotland, Wales or Northern Ireland as well as in England and duly did so.<sup>1240</sup> In due course, the trustees decided to exercise their power to appoint a corporate trustee. The individuals who would otherwise have been trustees then became, technically, directors of the company which was the corporate trust. The chief executive of the Caxton Foundation (“Caxton”) thus became a director.

Due to the terms of the deed, qualification for consideration for a grant was established by a third party, the Skipton Fund. It was not necessary to prove that the registrant had hepatitis: that had been done through the Skipton Fund assessing eligibility for a Stage 1 payment. However, a substantial number of those who had applied successfully to the Skipton Fund did not make any application to Caxton. This was an early concern of the Board.

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1237 Ministerial statement by the Secretary of State for Health, Andrew Lansley on Contaminated Blood 10 January 2011 DHSC5205794

1238 Caxton Foundation Trust Deed 28 March 2011 CAXT0000095\_006. Roger Evans stood down as a director/trustee in 2012 when he was appointed chair of the Macfarlane Trust. Charles Gore was from the Hepatitis C Trust; the other two had extensive experience of the Macfarlane Trust and Peter Stevens had been tasked in 2003-04 with helping to set up the Skipton Fund. Just as the Skipton Fund and the Eileen Trust had each been named after buildings which hosted discussions about their formation (Skipton House, Eileen House), this charity, the Caxton Foundation, drew its name from a place: Caxton Street, where Alliance House was situated.

1239 The minutes of the meeting of the founding trustees on 4 August 2011 explain the reason for this: “The Chairman expanded on the background to the establishment of the Caxton Foundation ... Time constraints meant that the Foundation could only be set up on an ‘England only’ basis; the Devolved Administrations (‘DAs’) have indicated that they will adopt both the new arrangements for Skipton and provide financial support for Caxton, but firm agreement, which would entail amendment of the Trust Deed, has yet to be reached ... it was expected that there would be additional funding from the DAs although it was not known how much or when the funds would be available.” Minutes of Caxton Foundation Founding Trustees and others meeting pp2-3 CAXT0000108\_017

1240 Caxton Foundation Trust Deed 28 March 2011 p15 schedule 5 CAXT0000095\_006

## Governance

Peter Stevens was chair of Caxton from 2011 until 2013. Ann Lloyd then became chair.<sup>1241</sup> She began in February 2013, and stood down as chair two years later<sup>1242</sup> when she considered that to continue might conflict with a role she had just accepted in the Welsh Health Service. Jan Barlow became chief executive in January 2013 in succession to Martin Harvey. She was also chief executive of the Macfarlane Trust at the same time. Whereas Roger Evans had seen a conflict between his being chair of the Macfarlane Trust and remaining on the Board of the Foundation, she saw no conflict in being chief executive of both charities,<sup>1243</sup> nor that there would be any particular difficulty in the Caxton Foundation being the nominal employer of all the staff working for both.<sup>1244</sup> It was arranged that the Caxton Foundation would employ all of the staff working at Alliance House.<sup>1245</sup> The aim was to save money and potentially make more available for beneficiaries,<sup>1246</sup> by spending less

1241 For a while she was also vice chair. She had been the chief executive of a health care trust for some nine years, before serving eight years as director general of Health and Social Care and chief executive of NHS Wales, and during that time had also been both a charity trustee and a member of the Board of the Patients' Association.

1242 March 2015.

1243 Jan Barlow Transcript 3 March 2021 pp115-116 INQY1000103

1244 There may well be a benefit in attracting better applicants to two roles in the same area, if it enabled better remuneration to be paid to one applicant rather than split between two. The inherent difficulty of potential conflict would have to be balanced against this. On analysis, having to face this choice is an example of some of the difficulty caused by the relatively small size of each charity.

1245 Written Statement of Christopher Pond para 32 WITN5265001

1246 The business case noted that administrative and management costs would be greater if economies of scale were not available. Business Case to enable the Macfarlane Trust to meet the Department of Health's objectives to properly resource the Caxton Foundation 15 April 2011 p5 CAXT0000095\_110  
The Department of Health for its part had laid down "*the (fairly obvious!) principles that economy and efficiency should be the watchwords; and that money spent on admin is money not available for charitable benefits.*" Draft Email from Jonathan Stopes-Roe to Martin Harvey 7 April 2011 p3 DHSC6698845. The Macfarlane Trust then received advice that the Trust would be acting outside its Objects if it were to provide services for nothing on this scale, and could not lawfully do so. Options were discussed on 13 May 2011 between Christopher FitzGerald, Peter Stevens and the Department of Health. The one which found favour was: "*Flip the power and have (the in future likely to be much larger) Caxton instead of MFT [Macfarlane Trust] as the service provider to the rest of 'the group.'*" Minutes of Alliance House and Department of Health meeting to discuss service provision for Alliance House operations 13 May 2011 p2 MACF0000023\_022

Christopher FitzGerald duly updated the National Support Services Committee ("NSSC") of the Macfarlane Trust on 20 May 2011: "*The advice [about whether the Macfarlane Trust could provide services for the other Alliance House Organisations] ... was that the limitations in [the Macfarlane] Trust Deed (including on the limited power to make amendments) were such that MFT could not provide such services at all, i.e. for reward or without charge ... As you will see the DH's [Department of Health] preferred way forward is to 'flip' the provision of services for 'Alliance House operations' so that they will be provided by Caxton to MFT and ET [Eileen Trust] (and to Skipton and MFET [Macfarlane and Eileen Trust]) rather than by MFT to Caxton and the others ... As to the practicalities, it will be necessary, in addition to transferring all responsibility for premises and employment arrangements to Caxton, for MFT to develop a Service Level Agreement under which Caxton will provide all the services MFT requires, just as we were expecting to do the other way around if the roles had been reversed.*" Email from Christopher FitzGerald to NSSC 20 May 2011 pp1-2 AHOH0000089

On 10 June 2011 the legal adviser to the Caxton Foundation gave the green light, observing: "*Once Caxton's objects have been changed it can provide services free of charge to MacFarlane Trust and to Eileen Trust. Caxton cannot provide services free of charge to the non-charities. Macfarlane (and subsequently Caxton) can justify the provision of services to SKF [Skipton Fund] and MFET which are non charities either on the basis that they are charged for and de minimis ... As legal adviser to Caxton Foundation I am satisfied, and have advised the trustees, that what is being proposed in the*

on the administration, though some of the complexities of having staff who could be directed to serve different bodies whose interests did not necessarily coincide necessitated a Joint Liaison Committee being set up.<sup>1247</sup>

Charles Lister was a director and vice chair of the Caxton Foundation from August 2011 to April 2015. He was a member of the committee which allocated grants, called the National Welfare Committee (“NWC”), from September 2011 until March 2012, and then chair of it until March 2014.<sup>1248</sup>

Caxton decided against having a user as a director: a paper authored by Peter Stevens and Charles Lister set out their view that the problem with appointing a “beneficiary trustee” was *“the absence of a ‘neutral’ outside body with rights of appointment, which means that beneficiary volunteers for the Board would most likely come from activist groups. Such people are likely to have difficulty with the requirement that they should not represent anybody or any cause outside the charity, but should at all times and only act in the best interests of the charity itself, not of its beneficiaries nor of any outside interest such as a campaign group; they might also find it difficult to accept that anything trustees learn about the charity should be confidential.”*<sup>1249</sup>

This view – in effect, saying anyone who was a user keen to advance the interests of other beneficiaries could not be trusted – is consistent with Peter Stevens’ distrust of the motives of Macfarlane beneficiaries.<sup>1250</sup> In this extract, by saying that the trustees should act *“in the best interest of the charity itself, not of its beneficiaries”* an entirely false demarcation was drawn: a charity’s purpose is to serve its beneficiaries in accordance with its objects. The best interests of the beneficiaries of a charity, taken as a whole, now and in the future are coterminous with those of the charity. The extract quoted above may simply have been a clumsy way of expressing that the trustees should have a broad rather than sectional view of the beneficiaries, but the words are set out as they were used, and as expressed they are objectionable. Charles Lister acknowledged in his evidence to the Inquiry that this was *“very badly worded”* and that there was a *“certain arrogance”* about this paper: he thought that they could have found a way of having a beneficiary trustee.<sup>1251</sup> He was right on this.

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*interests of saving VAT, falls within the powers of the Caxton Foundation.”* Email from Moira Protani to Department of Health’s Legal Services and Martin Harvey 10 June 2011 pp2-3 DHSC5669684. Thus this unusual arrangement was devised to save costs, including VAT liabilities.

1247 Ann Lloyd’s written statement described the purpose of the Liaison Committee as being *“to maintain a sound channel of communication between the organisation[s] to advise each other of changes in policy and strategy and to unearth discrepancies between the schemes.”* Written Statement of Ann Lloyd para 32 WITN5257001

1248 Charles Lister Transcript 25 March 2021 p123 INQY1000113

1249 Note on the possible recruitment of a director with experience of living with Hepatitis C 25 January 2013 CAXT0000109\_122

1250 See the chapter on the *Macfarlane Trust*.

1251 Charles Lister Transcript 25 March 2021 pp137-140 INQY1000113

## Underlying problems

Many of the problems the Macfarlane Trust had in 2011 beset Caxton too. To some extent that was because the proposed structures and governance arrangements were established in large part by Roger Evans and Peter Stevens. Because of their familiarity with the ways in which the Macfarlane Trust operated, they chose to set up Caxton to operate in a similar way.<sup>1252</sup> Many of the complaints by beneficiaries which followed echoed those made by the beneficiaries of the Macfarlane Trust. Save in respect of the ways they were organised there was, however, little if any overlap between the two charities – those who were beneficiaries of the Macfarlane or Eileen Trusts were excluded from benefits under Caxton, even though they were entitled to claim on the Skipton Fund.

It is telling that the different beneficiaries of Macfarlane and Caxton reacted in similar ways. This owed a lot to the policies, the structures, the organisation and those staff who were common to both. Before turning to the problems caused to relationships between the Foundation and its beneficiaries by the way the Foundation ran in practice (a topic which deserves rather fuller treatment), it must be acknowledged that it had underlying challenges to grapple with.

Central challenges were:

- (a) **Attracting those eligible.** Ensuring that those who were registered with the Skipton Fund were aware of and took advantage of the further assistance they could get from Caxton. The likelihood is that a very large number of these potential beneficiaries had significant need: this was demonstrated by an early survey of those who actually did register. Each was given a census form to fill in. Just over half of those who registered and returned the census had income which fell below what was recognised as the poverty line.<sup>1253</sup> The likelihood must be that those who had not yet applied would be the same.<sup>1254</sup> After Ann Lloyd became chair efforts made to let more potential applicants know of Caxton began to bear fruit: she brought energy and focus to the efforts to let more potential applicants know of the Foundation, putting together the proposal for Department of Health funding for the Skipton Fund in addition to extensive talks with the Hepatitis C Trust and Haemophilia Society.<sup>1255</sup>

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1252 Thus, as with Macfarlane, there was a failure to treat each registrant with sensitivity, with registrants seen as objects of charity rather than deserving of compensation. There was an onerous obligation on registered beneficiaries to return detailed financial information each year, to include information on the income of the beneficiary's partner or spouse. Caxton Foundation Personal Census Form Part 2 2011/2012 AHOH0000126. The practice of using unpublished office guidelines for staff to assess and authorise grant applications was modelled from the Macfarlane Trust.

1253 Regular Payments Scheme 6 November 2012 pp1-2 CAXT0000109\_085

1254 It might be speculated that it would be the poorer who were most keen to apply, and that therefore the earliest registrants might prove to be the poorest. However, those who did not have as great a level of earnings or earnings potential as others might also be thought to lack funds because of the effects of their illness, principal amongst which are depression and "brain fog", both of which are likely to make it more difficult for them to be in a position, if they were presented with the information necessary to apply, to be able to organise their affairs to do so, and to follow it through. There is no available evidence to show that later applicants to the Foundation were increasingly better off than earlier ones. In the absence of that, the assumption in the text is fully justified.

1255 Ann Lloyd Transcript 22 March 2021 pp131-133 INQY1000110



However, the fact remains that throughout its short life Caxton actively served only a small proportion of those who were entitled to its support.<sup>1256</sup>

More might have been achieved if the Government had made arrangements for the Skipton Fund to inform people who had registered with it about the existence of Caxton from the beginning.<sup>1257</sup> The Skipton Fund was, after all, an agent of the government, and could have been directed appropriately. Had this been done, there would have been no breach of data protection principles, and privacy would be preserved, for the choice of whether a beneficiary of the Skipton Fund then chose to have their details given to Caxton was in the beneficiary's power alone. The probability is that some more applicants would have come forward. The fact that Ann Lloyd's efforts bore some fruit leads to an inference, too, that more might have been done by the early trustees. Though in mitigation it must be borne in mind that those trustees had a lot to do in setting up the Foundation, nonetheless a primary responsibility was ensuring that as many as possible who might wish to make an application were enabled to do so, and an obvious route was to find a means of arranging that the Skipton Fund told successful applicants for awards from Skipton that there was a foundation specifically set up to fund further needs, and to offer to forward their details to it;

- (b) **Its relations with the government.** Since the government was in effect the sole funding agency, Caxton had the same feeling of unease as did the Macfarlane Trust at pressing its case for additional funds from government too strongly, and in particular in public. Though technically independent as a charity, it was expected to account for its expenditure to the government. It was not allowed to retain a reserve, which meant that its funding was treated as if it were a local authority dependent upon an annual budgetary round. This uncertainty of capital availability made long-term planning difficult. Not only that, it was understood that Caxton would report to

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1256 As of 31 March 2017, the Skipton Fund had made over 5,450 Stage 1 payments and 1,751 Stage 2 payments, whereas the Caxton Foundation had 1,323 beneficiaries, of whom 1,036 were primary beneficiaries infected with Hepatitis C. The Caxton Foundation Annual Financial Report for the Year Ended 31 March 2017 pp6-7 CAXT0000002\_047

1257 Charles Lister, one of the trustees, gave evidence that Skipton initially said data protection was the block to contacting their registrants; he questioned why the Department of Health did not help to trace potential applicants earlier than was done. He was also sure that more could have been done, particularly by the Department of Health given their resources; and also that more could possibly have been done by Caxton through a campaign to raise awareness, though it was not resourced to do so. It is fair to say the Board was alive to the issue but he cannot now remember why they did not do more than they did. Written Statement of Charles Lister paras 149-151, para 156 WITN4505001. It is however right to recognise that the Department of Health did, prior to 2014, take some steps to publicise Caxton, including making press releases, sending out bulletins (including to GPs), emailing relevant professional bodies (such as the British Association for the Study of the Liver, the British Viral Hepatitis Group and the British Society for Gastroenterology) and providing information about the Caxton Foundation on the Department of Health's website and the NHS Choices home page. Brief for meeting with Caxton Foundation Trustees 17 November 2011 pp4-5 DHSC6629618, Communications activity on contaminated blood payments DHSC5131026

the Department of Health that it had achieved the government’s “policy objectives” by the way in which it had spent the government’s money.<sup>1258</sup>

- (c) **Staffing levels.** These were barely adequate at the start. This was compounded in the early period of Caxton’s operation by the illness of the chief executive, Martin Harvey, who ultimately became unable to work any longer. However, the lack of sufficient staff able to perform necessary tasks, let alone to have time to consider improvements, underlay many of the operational problems which beset Caxton almost from its inception. Jan Barlow, when she became chief executive, set out (successfully in the eyes of Ann Lloyd)<sup>1259</sup> to overhaul the organisation to provide a more effective service to beneficiaries: she noted that when Caxton had been introduced “*there had just been one additional staff member who had been brought on to the team to deal with, if you like, the daily administration, and things hadn’t been looked at in the round.*”<sup>1260</sup>; and

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1258 The phrase comes from the *Statement of Financial Procedures* put in place by the Department of Health. It set out “*the governance, accountability and funding arrangements agreed between the Department of Health (DH) and the Trustees of the three Charities.*” *Statement of Financial Procedures* November 2014 p1 MACF0000061\_065. On the question whether this had any practical effect, the evidence is mixed. Ann Lloyd’s evidence was: “*Q. Is an arrangement where the Department of Health provides all the funds for the Caxton and then holds them to account as to how they spend it – is that arrangement, do you think, consistent with Caxton operating as an independent charity? A. No, but it was a fact of life. I did not feel beholden to the Department of Health. I just knew that we had to account effectively for the use of their resources for the purposes intended. Q. So do you think that the Caxton Foundation’s independence was impugned by that arrangement? A. No ... We were not instructed to undertake certain pieces of work*”. Ann Lloyd Transcript 22 March 2021 pp152-153 INQY1000110

Christopher Pond was of the view that: “*DH did not seek to influence the decisions ... with respect to the policy for allocating grants, how the CF [Caxton Foundation] should discharge its responsibilities to the beneficiaries, the kinds of applications the CF should grant or the quantum of the grants/payments it should make.*” Written Statement of Christopher Pond para 36 WITN5265001. I certainly accept this as his honest view, but note that it is almost inevitable that the amount of funding the Department of Health agreed to pay the Caxton Foundation each year must in reality have affected the quantum of grants and payments: if funds were limited, as the Caxton Foundation saw it (and they did) this realistically acted as a cap on payments.

Charles Lister, the thoughtfulness and reflective nature of whose evidence was impressive, said of the time that he was a trustee that he felt that the Caxton Foundation had “*travelled quite a long way over that three-year period in vastly improving the services that we provided.*” Since this suggested he thought there was further to go, he was asked “*Where would you have gone?*” and replied: “*I think, firstly, one of the questions that has been asked of other witnesses is ‘Why didn’t you push harder when the bid for the regular payments scheme was turned down?’ At the time it felt like: we’d had a firm Department of Health rejection; that’s all that we could have done about it. Again I wonder with the benefit of hindsight whether that was so. We had quite a compelling case, given poverty among other beneficiaries. We could have written to the Secretary of State about that. We could have engaged the Haemophilia Society and campaign groups in doing the same. So we needn’t, possibly, have taken ‘no’ for an answer, and again I think there was something about being – although we were not in any way in the pocket of the Department of Health, although the Department of Health did not interfere with our policies or anything about the day to day running of the organisation – and having served on a number of charity boards since then, I didn’t feel any different at Caxton than I have done on – you know, being on the board of an independent charity, but I do wonder whether the very fact that we were funded by the Department of Health, had an accountability relationship with the Department of Health, perhaps made us less inclined, for that reason, to challenge a decision that we were all vastly disappointed by.*” Charles Lister Transcript 26 March 2021 pp103-104 INQY1000114

1259 Written Statement of Ann Lloyd para 29 WITN5257001

1260 Jan Barlow Transcript 3 March 2021 p93 INQY1000103. The Department of Health should have ensured that staffing was adequate, or adequately funded, from the start since it knew

- (d) **Dealing with each beneficiary with sensitivity.** The chances were that each registered beneficiary would be as likely as those registered with the Macfarlane or Eileen Trusts to be aggrieved by the fact that they had received treatment which had resulted in serious life-limiting infections without any advance warning that that might be a consequence. To a significant extent, they had already seen their economic and social aspirations put out of their reach. Yet they were now to be seen as objects of charity rather than being deserving of compensation. A reluctance to apply for this reason – itself a by-product of the way the scheme was set up – was clear to Charles Lister, who thought that people applied rather reluctantly because Caxton was the only system available to provide support; like “*coming with a begging bowl*”<sup>1261</sup> and his view seems consistent generally with the evidence the Inquiry has received from applicants.

## Problems in the running of Caxton

### First year of operation: 2011-12

Caxton lacked an effective chief executive at the outset. Martin Harvey was ill, and went on to request early retirement in 2012.<sup>1262</sup>

Grants were initially paid by means of a “voucher system”. This not only carried an implication that recipients of relief could not be trusted with money to spend for the purposes claimed, but also exposed those using a voucher to the risk that they would be identified as suffering from Hepatitis C.<sup>1263</sup> Many were fearful of the consequences. In the popular imagination, Hepatitis C was linked with intravenous drug abuse, and with prostitution or promiscuity. It had overtones of HIV infection: and the stigma which people living with HIV had endured was notorious. Rightly, vouchers as means of grant aid were phased out after Jan Barlow took over as chief executive in early 2013.<sup>1264</sup>

By the end of 2012, the evidence as to the position of the Caxton Foundation was all one way. The Foundation was not working effectively. It took far too long to process applications. A dramatic illustration of this was given by Caxton’s National Welfare Committee (“NWC”) which reported that between September 2011 and March 2012 (the first six months of active operation) a third of applications were left undecided because more information was

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what the Foundation was intended to achieve and was responsible for providing the finance to enable it to do this.

1261 Charles Lister Transcript 26 March 2021 p98 INQY1000114

1262 The Caxton Foundation Annual Financial Report For The Year Ended 31 March 2013 p3 CAXT0000034\_008

1263 See for example: Written Statement of Lesley Brownless para 43 WITN1111001, Inquiry into the current support for those affected by the contaminated blood scandal in the UK January 2015 pp77-78, pp91-92 RLIT0000031

1264 Jan Barlow Transcript 3 March 2021 pp131-132 INQY1000103, Report from chief executive to Caxton Trustee Ltd Board meeting 2 May 2013 CAXT0000110\_016

needed.<sup>1265</sup> By the end of the next six months the situation had only marginally improved. Still more than one in five applications were left undecided. Over the first year, just over £2.25 million had been sought by way of grants; just over 30% had been granted, just over 40% declined and just under 30% left undecided.<sup>1266</sup> The audited accounts, however, submitted to the Charity Commission at the end of the year show a different picture – it might be inferred from them the amount left unspent was some 25% (a quarter rather than a third).<sup>1267</sup> It is unnecessary to resolve these differences (although it would be surprising that they should exist if the organisation were well run), since witnesses were in agreement that it took far too long to process early applications.<sup>1268</sup> Money left unspent at the end of the financial year did not roll over into the sums available for the next year, so delay simply added to the difficulties of making finance available.

The reasons given for postponing a decision on an application were generally that there was a need to seek further information, usually financial. Before Jan Barlow took over as chief executive, Caxton had acquired detailed financial information from all beneficiaries by means of an annual census to help the Foundation determine the outgoings and income of those who registered as beneficiaries.<sup>1269</sup> She queried why this was necessary. For instance, grants such as winter fuel payments were not means tested.<sup>1270</sup> The census was scrapped until a regular payment system was introduced.<sup>1271</sup> Charles Lister accepted in evidence that extracts were taken from census forms (while they lasted) to inform the NWC when it considered grant applications but the weakness of this was that it did not provide sufficient clarity.<sup>1272</sup> So long as census forms lasted and yet further information was required, beneficiaries felt they were being repeatedly quizzed about the same essential details of their income and expenditure. The consequence of this was that although over half the applicants were recognisably in poverty, and (by definition) had a chronic infection, they still had to provide more details, and then sometimes further details, and then wait.

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1265 Under the heading “Grants” the NWC reported that the total amount requested for the first six months of the period was £1,499,765.17 (very nearly £1.5 million) of which “£490,200.30” (very nearly £0.5 million) “was deferred (where no decision was made due to a lack of information).” Caxton Foundation NWC Report September 2011-September 2012 October 2012 p2 CAXT0000062\_072

1266 Caxton Foundation NWC Report September 2011-September 2012 October 2012 p2 CAXT0000062\_072

1267 The headline figures for October 2011 to March 2012 were approximately £524,000 received by the Foundation for disbursement, of which £400,000 had been spent. The Caxton Foundation Annual Financial Report for the Period from 1 October 2011 to 31 March 2012 p9 CAXT0000034\_010

1268 Charles Lister Transcript 26 March 2021 pp101-102 INQY1000114, Jan Barlow Transcript 3 March 2021 p211 INQY1000103

1269 This information was requested from each beneficiary irrespective of whether they were making an application to the Foundation, and required the beneficiary to provide detailed information about not only themselves but also their partner/spouse or civil partner. Caxton Foundation Personal Census Form Part 2 2011/2012 AH0H0000126. Charles Lister accepted in oral evidence that this would potentially have been onerous for some beneficiaries. Charles Lister Transcript 26 March 2021 pp64-66 INQY1000114

1270 Jan Barlow Transcript 3 March 2021 pp102-103 INQY1000103

1271 Charles Lister Transcript 26 March 2021 p64 INQY1000114

1272 Charles Lister Transcript 26 March 2021 p63 INQY1000114

## Subsequent years

Jan Barlow recognised that she had inherited a serious problem of delay in deciding on grant applications. She gave evidence that just one additional staff member had been brought onto the team to deal with the daily administration;<sup>1273</sup> and it had become obvious that there were a lot of beneficiaries on low incomes who needed regular support from Caxton.

Charles Lister also accepted that initially it had not been clear enough to beneficiaries what they might apply for. The website should have been more explicit. The annual report to the Charity Commissioners setting out the overall picture was not sent to beneficiaries.<sup>1274</sup>

Two months into Ann Lloyd's term of office, Jan Barlow and she expressed concerns to the Government that Caxton needed to develop a vision and strategy, to review the administrative processes and the competence and capability of staff, to improve communications with beneficiaries, and to better understand what their needs were.<sup>1275</sup>

It therefore became clear during the first 18 months of the Foundation's operation that the organisation was not working effectively, and in particular that beneficiaries were not being shown the sensitivity they merited.

Apart from occasional responses to issues raised by individual campaigners, there had been no formal dialogue with beneficiaries about what Caxton could deliver and how. This was in part due to the fact that there was no forum in which beneficiaries could meet either the staff or directors of the Foundation before the creation of the Partnership Group in 2013 and the newsletter did not start until December 2014.<sup>1276</sup>

Complaints were raised with the Parliamentary Under-Secretary of State for Public Health, Start for Life and Primary Care (then Anna Soubry) by a number of beneficiaries.<sup>1277</sup> She in turn raised those with Caxton. It was said that the Caxton Board appeared to be aloof and out of touch.<sup>1278</sup> The Minister was told that Caxton forms were excessively long and unnecessarily complicated. (It had used a form modelled on that used by the Macfarlane Trust).

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1273 Jan Barlow Transcript 3 March 2021 p93 INQY1000103

1274 Charles Lister Transcript 26 March 2021 pp57-58 INQY1000114

1275 The meeting was on 25 March 2013, recorded in the subsequent Board minutes: Minutes of Caxton Trustee Limited Board of Directors meeting 2 May 2013 p2 CAXT0000110\_034. A letter was sent the following year to the Under-Secretary of State for Public Health. Letter from Ann Lloyd to Jane Ellison 12 May 2014 p1 AHOH0000053

1276 This failure is even more striking given the fact that communication with beneficiaries was the subject of consideration from at least September 2011 when Charles Lister in a paper to the Board recommended that a newsletter was the minimum needed to communicate effectively with beneficiaries and sought further views as to how to enable two-way communication. Beneficiaries – Communication & Engagement September 2011 p2 CAXT0000108\_045. Minutes of Caxton Foundation Partnership Group meeting 11 June 2013 CAXT0000110\_048, Caxton Foundation December 2014 Update CAXT0000011\_006

1277 Relationships with the Beneficiary Community Issues Raised by Beneficiaries 2 February 2013 CAXT0000109\_115

1278 Jan Barlow did not accept that description, but it should be noted that it had been accepted internally at a Macfarlane/Caxton Liaison meeting on 19 December 2012 (shortly before Jan Barlow started) that the Foundation needed to make considerable improvements in its communications with its beneficiaries. Jan Barlow Transcript 3 March 2021 p96 INQY1000103, Minutes of Macfarlane/Caxton Liaison Committee meeting 19 December 2012 p3 CAXT0000068\_010

In June 2013 there was the first meeting of a “Partnership Group”.<sup>1279</sup> It agreed that there should be a wider annual forum to which all beneficiaries should be invited. This never happened. Jan Barlow explained that was because the Partnership Group had been “*slightly changed*” because it had been primarily campaigners and “*we were aware that there were a lot of beneficiaries who weren’t involved in campaign groups and, you know, who told us they didn’t feel represented by the campaign groups, so we ended up actually broadening membership of the group so that we had beneficiaries who weren’t campaigners involved*”.<sup>1280</sup>

As late as June 2013 still nothing was made available to beneficiaries in terms of guidelines or information about support for which they could apply.<sup>1281</sup> In the summer of 2014 some very limited information was published on the website,<sup>1282</sup> but this did not set out the amounts that were likely to be awarded. Some limited information was also published in the newsletter in December 2014, but again, this did not set out the likely awards that would be made.<sup>1283</sup> No proper or sufficient explanation was given to the Inquiry as to why Caxton needed to be so secretive.

Just over three years after it had begun operations, the All Party Parliamentary Group (“APPG”) Report in January 2015 added both further objective criticism and further weight to existing criticisms of its operation. It commented on “*many respondents’ dissatisfaction with the general demeanour of some trust staff, which they see as cold, dispassionate and unsympathetic*”.<sup>1284</sup> Asked in evidence if she had any comments on this observation by the APPG, Jan Barlow said “*No, not really.*”<sup>1285</sup> This seemed an expression of resigned acceptance of the force of what was being said: it was certainly not a repudiation of the view. Disappointingly she did not describe it as a call for urgent action, nor apparently see it as a reason to apologise. Even more disappointingly, when then asked if she took any practical steps in response, she did not recall. In short, where there should have been

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1279 Minutes of Caxton Foundation Partnership Group meeting 11 June 2013 CAXT0000110\_048

1280 Jan Barlow Transcript 3 March 2021 pp100-102 INQY1000103

1281 This was despite beneficiaries asking for the guidelines to be published and expressing concern about the lack of information. See for example Contaminated Blood Campaign Record of Caxton Foundation Partnership Group meeting 11 June 2013 p20 WITN2050101, Minutes of Caxton Foundation Partnership Group meeting 28 November 2013 p9 CAXT0000110\_094. The rationale for this appears to be that the office guidelines could not be published on the website since they only related to those things which the staff team could authorise without reference to the NWC and would therefore be misleading, so the Partnership Group of June 2013 was told. Minutes of Caxton Foundation Partnership Group meeting 11 June 2013 p3 CAXT0000110\_048

1282 This stated that the Foundation would “*make grants to fund the average cost of household items such as washing machines, tumble dryers, three piece suites etc, or make contributions only to other costs*” but did not specify what those average costs were. It maintained the decision not to publish the Office Guidelines as they were not financial limits and so would be misleading. Caxton Foundation Support to Beneficiaries 2014 p3 CAXT0000110\_131

1283 Caxton Foundation December 2014 Update pp2-3 CAXT0000011\_006

1284 Inquiry into the current support for those affected by the contaminated blood scandal in the UK January 2015 p80 RLIT0000031. This comment was general to the three charities which the APPG report considered, but it said it typified many beneficiaries’ concerns, and did not draw any distinction between the Caxton Foundation, Macfarlane Trust or Eileen Trust in this regard. The text contains several criticisms made to the APPG about the Caxton Foundation, just as it does about the Macfarlane Trust.

1285 Jan Barlow Transcript 3 March 2021 p145 INQY1000103, The Caxton Foundation Office Guidelines 2014 p2 CAXT0000103\_005’ after ‘INQY1000103

remedial swift action, there was no evidence that there was any. Though I have not lost sight of the fact that shortly after this Jan Barlow suffered a lengthy period of ill health, it was still her responsibility to see to such action being taken as best she could. She said nothing to satisfy the Inquiry that she had actively discharged that particular responsibility.<sup>1286</sup>

It was clear from the evidence that more should have been done to tell beneficiaries what they could apply for. As was the case with the Macfarlane Trust, the staff had guidelines to which they could refer (initially borrowed from the Macfarlane Trust).<sup>1287</sup> The reason advanced for restricting this to staff (given to the Partnership Group in June 2013) was that it might be misleading to publish it to beneficiaries: the fear was that beneficiaries might think this was all that was available, and not understand that they could make a claim beyond the categories mentioned in the office guidelines, which if they did would be considered (by the NWC).<sup>1288</sup> This was a poor reason. The office guidelines could have been published together with a statement explaining that was the case. Not to do so, however, left beneficiaries in the position that they were invited to register with a body which would give them money, but would not tell them how much they might get or what they might get it for. It is true that beneficiaries could contact the staff to ask them, and many did: and that the staff would be helpful as to what might be applied for when this happened. However, this had three drawbacks: first, it required a beneficiary to be proactive in finding out what might be the subject of a successful application; second, the staff, who were already hard pressed in dealing with applications, would have further demands on their time and goodwill; and third, much would depend upon the clarity and accuracy of the information given by the individual staff member, and this might have varied.

When an application was rejected, the absence of any clear published criteria for granting it in the first place meant that there were *“no fixed criteria in relation to household income, but each case was considered on its individual merits, and overall household income and expenditure levels, and disposable income, were reviewed ... beneficiaries were always advised as to the reason if a grant application was turned down, and the reason almost always related to an inability to determine charitable need”*.<sup>1289</sup> There was no information circulated in the office about appropriate levels of disposable income, nor were the beneficiaries told the maximum figures which were set out in the office guidelines. There was a general policy, however, that if there were *“in excess of £3,000 in grants, or more than four grants exceeding £3,000, then the request will be presented to the NWC.”*<sup>1290</sup> Asked

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1286 She did say however that *“we’d spent a lot of time, I believe, improving our offering to beneficiaries, even though some beneficiaries might not have felt that”*, that *“it was a much more efficient organisation at the end, from what it was when I found it”* and that *“instead of ... taking months and months and months”* for grant applications to be turned round, the turnaround time had reduced to a couple of weeks. She summarised by saying: *“I believe we had improved the system significantly”*. Jan Barlow Transcript 3 March 2021 p211 INQY1000103

1287 Charles Lister Transcript 26 March 2021 p33 INQY1000114

1288 Minutes of Caxton Foundation Partnership Group meeting 11 June 2013 p3 CAXT0000110\_048

1289 Minutes of Caxton Trustee Limited Board of Directors meeting 12 August 2015 p2 CAXT0000111\_057

1290 Jan Barlow Transcript 3 March 2021 p136 INQY1000103, The Caxton Foundation Office Guidelines 2014 p2 CAXT0000103\_005

what the NWC was supposed to do with the information, Jan Barlow's evidence was that it might inform other considerations.<sup>1291</sup>

In the absence of any fixed point of reference, consistency must have been difficult to ensure. In part this was mitigated by staff attending meetings to remind the NWC members of previous cases, with a view to ensuring some consistency. However, this system was hit and miss. Where a grant-making power has to be exercised in respect of people whose entitlement is equal, fairness towards those individuals requires the consistent exercise of discretion against established standards and principles. It is difficult to avoid the conclusion that although those involved were undoubtedly well meaning,<sup>1292</sup> the system as operated tended to unfairness.

An advantage of regular payments is that they may avoid the need for repeated applications for small sums. Another is that they may speed up the ability of an individual to respond to an urgent need; and a third that they are likely to be given upon a clear basis, so that they are not open to a challenge of inconsistency as between individual cases.

Though Caxton had determined at first to set up what could be seen as a regular payment scheme – £500 per winter as a fuel allowance – this was limited to a particular period of the year and intended for a particular purpose.<sup>1293</sup> It began to operate a broader regular payment scheme in 2014/15. The payments were designed to top up the income of a beneficiary to 60% (later 70%) of a median income.<sup>1294</sup> However, funds were severely restricted. Only 19%

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1291 Jan Barlow Transcript 3 March 2021 pp136-138 INQY1000103. It is possible to read from her evidence that there were three purposes: a) as a matter of good governance, larger requests should be escalated; b) a pattern of very regular requests might be an indication of financial difficulty and lead to support; and c) it might help policy on regular payments. It does not appear to have had any direct effect on the application itself.

1292 See for instance the evidence of Charles Lister (when challenged by Counsel about the absence of set criteria) that: *"It was effectively ... case by case, but then effectively applying a case law approach, if you like. So if we took a decision ... then we would make sure that we applied that same principle next time round, and there was always a dialogue between the Welfare Committee and staff to make sure that we were consistent in the way that the we awarded grants, because we were certainly concerned to have an approach of fairness that we wouldn't ... award something to one person and then refuse it to another or vice versa.*

*Q. You anticipated my next question, which is: is the risk of not having policies – – objective criteria committed to writing for all to see – – doesn't that give rise to the risk that there is inconsistent, and so therefore unfair, decision-making?*

*A. I mean, we were very conscious of not making unfair decision-making and, as well as looking at each case on its merits, checking what – – we always checked what had been awarded previously in similar circumstances to make sure we were consistent, and I think, from time to time, I certainly did a review of past cases as well, to try to ensure that we have been – – to monitor whether we had been consistent and pick out any instances where we weren't."* Charles Lister Transcript 26 March 2021 pp70-71 INQY1000114

1293 Winter fuel payments were first introduced in 2011 for beneficiaries with a household income of less than £14,000, which could be processed on a one-off basis by the welfare manager, with one-off winter fuel payments for households with higher incomes considered by the NWC. Minutes of Caxton Foundation NWC meeting 17 November 2011 p3 CAXT0000062\_001. For the following winter, the directors decided to make this payment for all primary beneficiaries and widows. Minutes of Caxton Trustee Limited Board of Directors meeting 1 November 2012 p4 CAXT0000109\_105

1294 Written Statement of Charles Lister paras 315-318 WITN4505001



of the beneficiaries and the bereaved received such payments during that financial year.<sup>1295</sup> Pressure was put upon the funding levels by a rise in the number of beneficiaries between whom the annual financial allocation was to be shared. This rise came about because about a third of the way through the 2014/15 financial year the Department of Health asked the Skipton Fund to attempt to contact anyone who had ever received a Skipton Stage 1 payment, but with whom there had been no subsequent communication. The result was that the number of Caxton beneficiaries rose by nearly 60%.<sup>1296</sup> For 2014/15 however, the pressure on funds was such that the annual fuel allowance had to be reduced from the £500 beneficiaries had been promised to £350 in the winter: this was later to be topped up by £150 in March the following year. Since government funding was year by year, this experience of an expected (and promised) benefit not being paid in full increased feelings of financial insecurity for the following year, although the annual report did say that the regular payment scheme would continue.<sup>1297</sup> It should be one of the great advantages of a regular payment scheme that the regular receipt of money enables the recipient to make longer-term plans. The experience of finance not being available to cover fully the winter fuel allowances, coupled with the fact that the budget ran from year to year and might be determined finally after the year had already started, meant this advantage was less than it might have been: there could not be confidence that the expected amounts would actually materialise, especially if additional beneficiaries were again to come forward. It was not known how many would, so this could not easily be planned for.

One of the priorities which Ann Lloyd had set herself when she began as chair was identifying new beneficiaries,<sup>1298</sup> so that Caxton could serve an unsatisfied demand. Under the Trust deed establishing Caxton, it said: “*Under the Skipton Fund Agreement (2) and at the request of the Trustees, the Skipton Fund is (subject to compliance with data protection laws) required to notify the Trustees of the identity of the Primary Beneficiaries.*”<sup>1299</sup>

When asked about this, Ann Lloyd said she had never been given a copy of the Trust deed and did not believe that the Caxton trustees appreciated what was said in it.<sup>1300</sup> There had been discussions with Skipton, and the chief executive had discussed the matter with Skipton. The Skipton Fund had not raised any issue of data protection as a reason for not providing information, but had relied upon staffing.<sup>1301</sup> Ann Lloyd, who described herself as “*always a bit impatient to get things done*”, thinks that perhaps she should have pushed

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1295 The Caxton Foundation Annual Financial Report for the Year Ended 31 March 2015 p10 CAXT0000035\_078

1296 The Caxton Foundation Annual Financial Report for the Year Ended 31 March 2015 p3 CAXT0000035\_078

1297 The Caxton Foundation Annual Financial Report for the Year Ended 31 March 2015 pp9-10 CAXT0000035\_078

1298 Minutes of Caxton Trustee Limited Board of Directors meeting 2 May 2013 p2 CAXT0000110\_034

1299 Caxton Foundation Trust Deed - Schedule 5 28 March 2011 p15 CAXT0000095\_006. Though the Skipton Fund was not a party to the Trust deed, under its own governing instruments it was the agent of the Secretary of State for Health and obliged to follow any direction made to it.

1300 Ann Lloyd Transcript 22 March 2021 pp130-131 INQY1000110

1301 Ann Lloyd Transcript 22 March 2021 p132 INQY1000110

harder to increase the numbers who applied.<sup>1302</sup> She did have some success. When she first came to the Caxton Foundation 555 primary beneficiaries were registered. By the time of the annual report of 31 March 2015, 1,080 beneficiaries were registered.<sup>1303</sup> The number had doubled in two years, and was increasing.

Increasing numbers of those entitled implies a need for greater funding to be available if those now coming forward are to have the same level of support as those who have previously benefited from the same Foundation. That might be thought to demand further commitment of resources by the government. Jan Barlow had made a request of the Department of Health for additional funding once it had become clear that Skipton were going to contact their beneficiaries to inform them about the Foundation. She was told that there was no additional funding and the Foundation would have to manage within its means.<sup>1304</sup>

A business case was accordingly prepared with a view to increasing the funding available for 2014-15.<sup>1305</sup> The business case was rejected in a letter of 19 February 2014. The letter said, simply:

*“Ministers have decided that this is not the right time for an uplift in allocation, whilst they continue to consider how best to address a range of issues about the system of support available to those affected by contaminated blood, many of which were highlighted during the Westminster Hall debate on the topic on 29 October 2013. I am also sorry that I am not yet able to confirm the Caxton Foundation allocation for 2014/15 as ministers are still considering the overall apportionment of spend across the whole of the health system.” The letter ended with: “I would be happy to meet with you, if you would find it helpful to discuss your plans for 14/15.”*<sup>1306</sup>

The business case submitted by the Foundation for funding for 2014/15 was thus rejected. No further funding was to be forthcoming for its proposals, and there remained uncertainties about the allocation for the Caxton Foundation. In consequence, amendments had to be made to the regular payments scheme which had been proposed – regular payments could be made to those whose income was less than 70% of median income, rather than the 80% which had been proposed; the scheme could not take account of any more than two children in a household; and it had to take into account any regular payment made at Skipton Stage

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1302 Ann Lloyd Transcript 22 March 2021 p133 INQY1000110

1303 Ann Lloyd Transcript 22 March 2021 p174 INQY1000110, The Caxton Foundation Annual Financial Report for the Year Ended 31 March 2015 p8 CAXT0000035\_078

1304 Minutes of Caxton Trustee Limited Board of Directors meeting 22 October 2014 p1 CAXT0000110\_166, Jan Barlow Transcript 3 March 2021 p107-110 INQY1000103

1305 Business case for increased funding for the Caxton Foundation from 2014/15 for a regular payment scheme 2014 AH0H0000001. The proposal was to top up the income of a beneficiary to 80% of a median income without taking account of household income from people beyond the primary beneficiary and partner if applicable, Skipton Stage 2 regular payments and child-related benefits. Charles Lister described the inclusion of these as “*unfortunate but necessary compromises*” to implement regular payments when the Department of Health had rejected the business case. Written Statement of Charles Lister para 316 WITN4505001

1306 Letter from Dr Ailsa Wight to Ann Lloyd 19 February 2014 CAXT0000110\_089

2, which meant that those who “*were the illest, the most unwell, would, in all likelihood, not obtain a regular payment from the Caxton Fund [sic]*”.<sup>1307</sup> Ann Lloyd described how she had been worried that “*we simply would not be able to maintain a regular payment scheme and all the additional beneficiaries within our allocation*”.<sup>1308</sup>

Charles Lister wondered (very much in retrospect though) if perhaps being fully funded by the Department of Health made the Board less inclined to challenge the level of funding.<sup>1309</sup>

In April 2013 an incident occurred. A number of members of the Contaminated Blood Campaign visited Alliance House, wishing to see Ann Lloyd and Jan Barlow. They understood they had a standing invitation to do so.<sup>1310</sup> They had no specific invitation for that date, and were seen by the staff to have barged in, in numbers sufficient to be intimidatory. This led to aggressive correspondence, initiated by Caxton officials who had not themselves been present and who expressed views about what had happened which were derived as hearsay from second-hand recollection, with little or no attempt to speak to those said to be directly involved.<sup>1311</sup> The significance of the incident is that it reflects the poor state of relations between those running or working for Caxton and people who were meant to be helped by it. Ann Lloyd told the Inquiry that she made an apology for this.

## Commentary

In summary, the difficulties which beset the Caxton Foundation, and contributed to poor relations between beneficiaries and the Foundation, were principally:

- (a) an absence of a user trustee (although Charles Gore had experience of Hepatitis C and Margaret Kennedy was appointed in 2014 as someone who could represent the user voice<sup>1312</sup>);
- (b) the close links with the Macfarlane Trust where dissatisfaction had been expressed by beneficiaries;
- (c) the failure to take more proactive steps to ensure that those who would be eligible to apply to Caxton were aware of its existence;
- (d) the poorer practices during Caxton’s first year of operation;
- (e) the initial shortage of staff to achieve a proper turnaround of applications;
- (f) the frequent referral back to applicants for further information;

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1307 Ann Lloyd Transcript 22 March 2021 pp170-171 INQY1000110

1308 Ann Lloyd Transcript 22 March 2021 pp171-172 INQY1000110

1309 Charles Lister Transcript 26 March 2021 pp103-104 INQY1000114

1310 An earlier Q&A suggested they did: “*Can I visit the office? Yes, of course. Just let us know when you want to come so the member of staff you want to see can arrange to be available or take pot luck!*”  
The Caxton Foundation Questions and Answers p2 CAXT0000079\_005

1311 Jan Barlow Transcript 3 March 2021 pp175-177 INQY1000103, Ann Lloyd Transcript 22 March 2021 pp144-149 INQY1000110

1312 Written Statement of Margaret Kennedy para 12 WITN0911001

- (g) the feeling of many that they were supplicants rather than applicants;
- (h) a lack of any clear information as to what might be applied for, and on what basis an application was determined, coupled with uninformative rejections of applications; and
- (i) the absence of any developed forum for an exchange of views between the Board and the beneficiaries.

The report of the APPG mentioned above recognised this at the time.

To Caxton's credit, it was proactive in supporting beneficiaries dealing with debt. Charles Lister, and the Board, recognised that simply giving grant aid to an individual attempting to service mounting debt might achieve little in the long run. It was proactive in taking steps to provide the services of Pennysmart, Jayne Bellis, and Neil Bateman, to advise beneficiaries who wanted their help how they might access other sources of funding, and manage those they had: the debt counsellors were able to act as advocates for some of the beneficiaries and arranged to manage their debt on favourable terms.<sup>1313</sup> Caxton's success in doing this deserves to be recognised as an achievement.

Much of this chapter has been critical of Caxton, in part because of the way in which the Government set it up, in part because the Government did not provide sufficient funds to meet the reasonable needs of the disproportionately poor membership of the class of beneficiaries and bereaved, and in part because of failures in organisation, administration and attitude. However, there was no lack of desire on the part, in particular, of Ann Lloyd and Charles Lister to do their best for a badly disadvantaged group.

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1313 Charles Lister Transcript 26 March 2021 pp34-46 INQY1000114. Pennysmart provided debt counselling and money management advice and advocacy support. Written Statement of Jayne Bellis WITN5256001. Neil Bateman was an independent benefits adviser to the Caxton Foundation from December 2011 until its closure. Neil Bateman Transcript 12 March 2021 pp102-221 INQY1000109, Written Statement of Neil Bateman WITN3487001

## 6.10 Medical Records

The importance of maintaining accurate medical records, along with unhampered patient access to them, is explored in this chapter. It outlines the legislative and policy provisions for retention of records over time and gives examples of failures of these. It describes individuals' concerns about the quality and content of their medical records and the resulting difficulties with claiming support.

### Key Dates

**1952** WHO identifies record keeping as key to reducing the risks of hepatitis.

**1961** onwards guidance and circulars issued containing advice as to the retention and disposal of medical records.

**2019** haemophilia patients informed that paper forms had been archived but not entered when digitising the National Haemophilia Database.

**2024** latest iteration of the General Medical Council *Good medical practice* which sets out the professional obligations on doctors in relation to record keeping.

### People

**Professor David Armstrong** Medicine and Sociology, King's College London; member, Public Health and Administration Expert Group, Infected Blood Inquiry

**Rob Behrens** Parliamentary and Health Service Ombudsman, England

**Professor Charles Hay** director of the National Haemophilia Database

### Abbreviations

**UKHCDO** UK Haemophilia Centre Doctors' Organisation

**WHO** World Health Organization

One of the pillars on which the reduction of risks from serum hepatitis was based, as identified by the Expert Committee on Hepatitis of the World Health Organization (“WHO”) in 1952, was the keeping of accurate records (and the reporting which would come with it).<sup>1314</sup> As this section shows, the UK failed in achieving this. So widespread was its failure that many of those who would have expected record-keeping to be at least more or less accurate and reasonably complete, even if not perfect, have wondered whether in the case of their particular infections the reason is more than the effects of pressures of work, muddle and incompetence.

The destruction and disappearance of medical records has caused both practical difficulties and significant anxieties for individuals who were infected and their family members. The lookback exercises for both HIV and Hepatitis C have been severely hampered by difficulties with medical records.<sup>1315</sup> Practically, where medical records have been destroyed or could not be obtained from hospitals, GPs and health boards, individuals have struggled to evidence the source of their infection for the purposes of the financial assistance schemes.

Emotionally, for adults who were infected as children there is a particular desire to understand what happened to them as children. For family members of deceased individuals there is also a desire to understand family members’ treatment and what caused their death, particularly so for children seeking to reconstruct what happened to their parent or parents who were infected. The emotional toll of trying to obtain the records has been significant for some people.

The responses to people who have tried to obtain their records have been very varied with some hospital trusts and boards failing to respond or providing vague replies while others have been better equipped to provide a speedy, substantive response. For others there have been long delays and hard work involved in obtaining records.<sup>1316</sup> Cressida Haughton, whose father was infected with Hepatitis C, described trying to obtain her late father’s medical records as “*like a battle of wills*”.<sup>1317</sup>

Over time the legal framework that applies to medical records has changed with guidance being issued over the years requiring records to be kept for specified retention periods. Nevertheless, accessing records has continued to be problematic. A fundamental difficulty lies in the fact that there was, and remains, no central system where medical records are held. Therefore, individuals have to apply to specific NHS trusts, health boards or GP practices. For those patients with complex health needs, who have received treatment over a number of years, from a number of hospitals and/or have moved throughout England, Wales, Scotland or Northern Ireland over the course of their lives, this is particularly challenging. Changes to the NHS, with the closure of a large number of hospitals, particularly maternity hospitals, have brought other challenges as individuals have found that hospitals

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1314 WHO Expert Committee on Hepatitis First Report March 1953 p17 RLIT0000215

1315 See the chapters on *HIV Lookback* and *Hepatitis C Lookback*.

1316 For example Written Statement of ANON para 6 WITN1319001

1317 Written Statement of Cressida Haughton p2 WITN3125001

have long since closed down and medical records have been destroyed without any prior notification to patients.

For some hospitals there have been environmental issues that have led to the loss or destruction of records: floods, fires, sewage leaks. For many others, the administrative difficulties of keeping track of large volumes of records, patients' name or address changes, or their movement across different departments and clinicians through the hospital have proved too much and records have been lost. The transition from paper records to electronic records (via microfiche records in some cases) has also resulted in a number of records disappearing, although going forwards the use of electronic records may well avoid many of the issues identified here.

These explanations address the majority of the cases where records have not been found despite requests, being either lost or destroyed. However, some examples that have been provided to the Inquiry raise concerns that records may have been destroyed or amended intentionally for malign purposes or, at the least, to avoid difficult questions.

## The legislative and policy framework for retention of medical records

Each of the four nations had different legislative provisions but they were broadly similar in what they sought to achieve. In England, the Public Records Act 1958, as amended by the Public Records Act 1967, provides that records of NHS organisations are public records.<sup>1318</sup> The Secretary of State for Health and Social Care and all NHS organisations have a duty under the Act to make arrangements for the safekeeping and disposal of all types of records. Following the enactment of the Government of Wales Act 2006, the Public Records Act continues to apply to the records of health service hospitals in Wales pursuant to section 148(1)(e) of the Government of Wales Act 2006.

In Scotland, in 1937 the Public Records (Scotland) Act was passed.<sup>1319</sup> Section 12 of that Act provided that regulations could be made regarding the disposal by destruction of records "*which are of insufficient value to justify their preservation*". In 1940, a set of regulations were passed which appear to have required the Lord Justice General, the Lord President and the Secretary of State to produce schedules of those documents considered to be of insufficient value to be retained by the Keeper of the Records of Scotland.<sup>1320</sup> One such schedule the Inquiry has located dated July 1958 and entitled *The Scottish Hospital Service Destruction of Records*<sup>1321</sup> provides that hospital records (including blood transfusion records) must be kept for six years after the patient's treatment at the hospital, or three years if the patient dies at the hospital. This is a minimum period: the memorandum accompanying the schedules makes this clear – it "*merely sets out the minimum period at the expiry of which hospital*

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1318 Public Records Act 1958, First Schedule RLIT0002245

1319 Public Records (Scotland) Act 1937 RLIT0001720

1320 S.R. & O. 1940/2107

1321 Scottish Hospital Service Destruction of Hospital Records 30 July 1958 PRSE0000552

authorities may destroy certain classes of records, but it places no obligation upon them to do so, then or later.”<sup>1322</sup> This guidance was not updated until 1 December 1993.

The guidance across time is summarised as follows:

Document name and date	Adult records	Obstetric records	Paediatric records
<b>England</b>			
1961: Retention and Disposal Schedule HM(61)73 <sup>1323</sup>	6 years after the conclusion of treatment or 6 years after the death of a patient. Summaries of clinical notes should be preserved.		
1980: Health Services Management: Retention of Personal Health Records (for possible use in litigation) HM(80)7 <sup>1324</sup>	8 years after the conclusion of treatment or 8 years after the death of a patient.	25 years	Until the patient’s 25th birthday or 8 years after the last entry, whichever is longer.
1999: For the record: Managing records in NHS Trusts and health authorities HSC 1999/053 <sup>1325</sup>	8 years after conclusion of the treatment or death.	25 years	Until the patient’s 25th birthday or 26th if the young person was 17 at the conclusion of the treatment, or 8 years after the patient’s death if death occurred before the patient was 18.

1322 Scottish Hospital Service Destruction of Hospital Records 30 July 1958 p1 PRSE0000552. Emphasis in original.

1323 Summarised in Thompson *Wirral Hospital Records* Journal of the Society of Archivists April 1985 RLIT0001174

1324 Summarised in Nicol and Sheppard *Why keep hospital clinical records?* British Medical Journal 26 January 1985 RLIT0001704

1325 NHS Circular *For the Record: Managing records in NHS Trusts and Health Authorities* 19 March 1999 RLIT0001726



Document name and date	Adult records	Obstetric records	Paediatric records
2006: Records Management Part 1 <sup>1326</sup> and part 2. <sup>1327</sup>	Hospital records 8 years (except clinical trials). GP records 10 years after patient died or had permanently left the country. Patients diagnosed with Creutzfeldt-Jakob disease, retention for 30 years from diagnosis, including for deceased patients. Oncology records should be retained for 30 years.	25 years	Until the patient's 25th birthday or 26th if young person was 17 at conclusion of treatment, or 8 years after death. If the illness or death could have potential relevance to adult conditions or have genetic implications for the family of the deceased, clinician advice should be sought on longer retention.
2021: Records Management Code of Practice for Health and Social Care <sup>1328</sup>	Usually 8 years retention. Where "pioneering or innovative treatment" is involved, long term preservation should be discussed. GP records for deceased patients retained for 10 years. After 10 years of no contact and no transfer request, GPs should check the Personal Demographics Service for indication of death or other reason for no contact. <sup>1329</sup> Where no reason is apparent, records must be kept. <sup>1330</sup>		Retention, including midwifery records, up to 25th birthday, or 26th birthday if the patient was aged 17 when the treatment ended.
<b>Wales</b>			
1980: Welsh Circular WBC(80)9	8 years after the conclusion of treatment or 8 years after the death of a patient.	25 years	Until their 25th birthday or 8 years after the last entry, whichever is longer.

1326 Department of Health *Records Management: NHS Code of Practice Part 1* 30 March 2006 RLIT0002243

1327 Department of Health *Records Management: NHS Code of Practice Part 2* January 2009 RLIT0002244

1328 NHS England *Records Management Code of Practice for Health and Social Care 2021* August 2021 RLIT0002240

1329 Appendix II Retention Schedule of the Code pp26-27 RLIT0002240

1330 Appendix II Retention Schedule of the Code p27 RLIT0002240

Document name and date	Adult records	Obstetric records	Paediatric records
1999: Welsh Health Circular WHC(99)7 Preservation, Retention and Destruction of GP General Medical Services Records Relating to Patients <sup>1331</sup>	10 years after conclusion of treatment, the patient's death or after the patient had permanently left the country.	25 years	Retention until the patient's 25th birthday or 26th if an entry was made when the young person was 17; or 10 years after death of a patient if sooner.
2000: For the Record: Managing Records in NHS Trusts and Health Authorities WHC (2000) 71 <sup>1332</sup>	8 years	25 years	Retention until the patient's 25th birthday, or 26th if the young person was 17 at the conclusion of treatment; or 8 years after the patient's death if death occurred before the 18th birthday.
2022: Records Management Code of Practice for Health and Social Care 2022: A Guide to the Management of Health and Social Care Records WG44221 <sup>1333</sup> and circular WHC (2022) 008 <sup>1334</sup>	8 years. GP records for deceased patients: 10 years. Oncology records: 30 years, or 8 years after death. Creutzfeldt-Jakob disease: 30 years or 10 years after death. Long-term illness, or illness that may reoccur: 20 years or 10 years after death. Blood bank register: 30 years minimum.	25 years	Up to the patient's 25th or 26th birthday.

1331 Welsh Health Circular *Preservation, Retention and Destruction of GP General Medical Services Records Relating to Patients* 18 January 1999 RLIT0002241

1332 Welsh Health Circular *For the Record: Managing Records in NHS Trusts and Health Authorities* July 2000 RLIT0001725

1333 Welsh Government *Records Management Code of Practice for Health and Social Care 2022: A Guide to the Management of Health and Social Care Records* February 2022 RLIT0001718

1334 Welsh Health Circular *New Records Management Code of Practice for Health and Care 2022* July 2022 RLIT0001724

Document name and date	Adult records	Obstetric records	Paediatric records
<b>Scotland</b>			
1993: Guidance for the Retention and Destruction of Health Records MEL(1993)152 <sup>1335</sup>	6 years from the date of the last recorded entry or 3 years after the death of the patient. Consideration to be given to longer retention for patients with genetic disorders. For GP records held by health boards, retention for 3 years after the death of the patient. Retention for 6 years or some other agreed period where the patient had left the country temporarily with an intention to return. Oncology records for 3 years after their death. Clinical trial records to be kept for a minimum of 15 years.	25 years after the birth of a child.	Retention until the patient reached the age of 25, or 3 years after death if this is earlier.
2006: Management, Retention and Disposal of Administrative Records HDL (2006) 28 <sup>1336</sup>	Confirmed the continuation of the 1993 guidance.		

1335 NHS Scotland Management Executive *Guidance for the Retention and Destruction of Health Records* 1 December 1993 SCGV0000038\_042

1336 NHS Scotland Health Department *The Management, Retention and Disposal of Administrative Records* April 2006 RLIT0001171

Document name and date	Adult records	Obstetric records	Paediatric records
2008: Scottish Government Records Management: Health and Social Care Code of Practice <sup>1337</sup>	6 years after the date of the last entry, or 3 years from the date of death if earlier. Donor records (blood and transplantation) 30 years after donation. GP records to be retained for the lifetime of the patient and until 3 years after their death. Oncology records: 30 years.		Until the person's 25th birthday, or 26th if they were 17 at the conclusion of the treatment, or 3 years after death. Consideration to be given to longer retention if the illness or death could have relevance to adult conditions or genetic implications.
2020 version of this Code of Practice. <sup>1338</sup>	Retention periods remain the same.	Retention periods remain the same.	Retention periods remain the same.
<b>Northern Ireland</b>			
1962: Northern Ireland Hospital Authority Circular HMC 75/62 <sup>1339</sup>	6 years after the conclusion of treatment and 3 years after the patient's death if they died in hospital. Blood transfusion service lab records retention for minimum of 1 year after death of donor.		
1983: Department of Health and Social Services Circular HSS (OS)1/83 <sup>1340</sup> (not including Central Services Authority records)	8 years after the death of a patient or conclusion of treatment.	25 years	Until 25th birthday or 8 years after the last entry, if longer.

1337 NHS Scotland *Scottish Government Records Management: NHS Code of Practice Version 1* June 2008 RLIT0001146. Updated versions were issued in March 2010 and January 2012 with the same retention periods. NHS Scotland *Scottish Government Records Management: NHS Code of Practice Version 2* March 2010 RLIT0001151, NHS Scotland *Scottish Government Records Management: NHS Code of Practice Version 2.1* January 2012 RLIT0001152

1338 Written Statement of Louise Williams para 1.4 WITN4690014, *Scottish Government Records Management: Health and Social Care Code of Practice* 18 May 2020 RLIT0001150

1339 Northern Ireland Hospital Authority Circular *Preservation and Destruction of Hospital Service Records* 28 September 1962 WITN3449019

1340 Department of Health and Social Services Circular *Retention of Personal Health Records (For Possible Use in Litigation)* August 1983 WITN3449020

Document name and date	Adult records	Obstetric records	Paediatric records
1996: Health and Social Services Executive Circular (SE) 3/96 Retention of Personal Health Records (for possible use in litigation) HSSE (SC) 3196 <sup>1341</sup>	8 years after the last entry.	25 years	Until patient turned 25, or for 8 years after the last entry or their death, whichever was longer.
2000: Health and Social Services Circular (PCCD) 1/2000 Preservation, Retention and Destruction of GP Records <sup>1342</sup>	10 years after the conclusion of treatment, the patient's death or the date on which the patient permanently left the country. Patient records should be held within the Central Services Agency when a patient dies or goes to live permanently in another country.	25 years	Until the patient's 25th birthday or 26th if an entry was made when the young person was 17; or 10 years after death of the patient if sooner.
2004: Good Management, Good Records 218/2004 <sup>1343</sup> (not including GP records).	8 years after the conclusion of treatment.		Until the 25th birthday (or 26th birthday if they were 17 at the conclusion of treatment), or 8 years after death if death occurred before the age of 18.

1341 Health and Social Services Executive Circular *Retention of Personal Health Records (For Possible Use in Litigation)* November 1996 WITN3449021

1342 Health and Social Services Circular: *Preservation, Retention and Destruction of GP Medical Records* 6 January 2000 RLIT0002236

1343 Department of Health, Social Services and Public Safety *Good Management, Good Records* 2004 WITN3449009

Document name and date	Adult records	Obstetric records	Paediatric records
2011: Good Management Good Records. <sup>1344</sup> Applicable to all health and social care records	8 years after the conclusion of treatment or death. GP should retain their records until the patient dies or is no longer a patient of the GP. Records should then be sent to the Health and Social Care Board <sup>1345</sup> , which should retain for 10 years after the person's death or they have left the country permanently.		Until 25th birthday (or 26th if they were 17 at the conclusion of treatment or 8 years after the last entry, whichever is longer), or 8 years after death if death occurred before the age of 18.

**Table 1. Summary of medical records retention guidance**

It should be noted that these are the specific pieces of guidance dealing with the retention of medical records. Other parts of legislation form a wider legal framework that addresses a range of important issues such as the right to access health records,<sup>1346</sup> the requirement to keep clear, accurate, and legible records,<sup>1347</sup> the requirement to keep certain

1344 Department of Health, Social Services and Public Safety *Records Management: Good Management, Good Records* November 2011 WITN3449011

1345 Albeit this closed in March 2022, but the guidance has not been updated to take account of this.

1346 See for example the Access to Health Records Act 1990 (as amended) which governs the rights of access to deceased patient health records by specified people.

1347 The main source of the professional obligation on doctors is the: General Medical Council's *Good medical practice*. The current version (January 2024) deals with the requirement in very strong terms: "You must make sure that formal records of your work (including patients' records) are clear, accurate, contemporaneous and legible.

*You should take a proportionate approach to the level of detail but patients' records should usually include:*

*a relevant clinical findings*

*b drugs, investigations or treatments proposed, provided or prescribed*

*c the information shared with patients*

*d concerns or preferences expressed by the patient that might be relevant to their ongoing care, and whether these were addressed*

*e information about any reasonable adjustments and communication support preferences*

*f decisions made, actions agreed (including decisions to take no action) and when/whether decisions should be reviewed*

*g who is creating the record and when.*

*You must keep records that contain personal information about patients, colleagues or others securely, and in line with any data protection law requirements and you must follow our guidance on 'Confidentiality: good practice in handling patient information.'*

See also: General Medical Council *Protecting children and young people* paras 52-60 3 September 2012 RLIT0002242

information confidential<sup>1348</sup> and to abide by data protection laws,<sup>1349</sup> and of course freedom of information.<sup>1350</sup>

The Inquiry obtained evidence from a sample of NHS trusts and health boards across the UK which showed that while trusts and boards were able to confirm that they currently follow national guidance and provide current policies on document destruction,<sup>1351</sup> and they believe that guidance was followed historically,<sup>1352</sup> copies of older policies were generally unavailable.<sup>1353</sup> In Lancashire, the Trust’s procedural documents – not medical records – were themselves subject to a retention period of ten years “*after which time the items were destroyed both electronically and in paper format.*”<sup>1354</sup> This position changed in 2018 and all procedural documents are now held electronically.<sup>1355</sup> University Hospitals Birmingham NHS Foundation Trust was able to provide retention policies from 1999 onwards.<sup>1356</sup> The 1999 policy mirrors the national guidance. Although Cardiff and Vale University Health Board were unable to find policies in place prior to 2013, they found a letter to all clinicians dated 18 August 1999 confirming that a policy had been approved for implementation in 1999 allowing for the destruction of records of patients who had not attended for treatment in over eight years, or 25 years for obstetrics and paediatrics.<sup>1357</sup>

The existence of retention policies providing for destruction after a period of time does not mean that records were necessarily destroyed. One man who contacted the hospital for his medical records says: “*by chance I knew the woman who was dealing with my request. She said ‘you’re lucky as they should have been destroyed three years ago but we actually still have them.’ I paid the fifty pounds to obtain my records, which included evidence of my blood transfusions.*” This was significant because until then he had been told that there was no evidence to suggest he had ever had a blood transfusion. Once he had been provided with copies of his medical records, he was successful in his application to the Skipton Fund.<sup>1358</sup>

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1348 See for example the Caldicott Principles: National Data Guardian for Health and Social Care *The Eight Caldicott Principles* December 2020 RLIT0002238

1349 The current data protection law being set out in the Data Protection Act 2018, which governs how records, information and personal data are managed, and the UK General Data Protection Regulation 2016, which came into effect on 1 January 2021.

1350 The Freedom of Information Act 2000 which came into force in January 2005 governs access to non-personal public records. For Scotland see the Freedom of Information (Scotland) Act 2002.

1351 For example Written Statement of Louise Williams WITN4690014

1352 For example Written Statement of Iain Paterson WITN6911007

1353 Written Statement of Louise Williams para 1.1.1 WITN4690014, Written Statement of Eric Sanders para 1 WITN7125001, Written Statement of Suzanne Rankin para 4 WITN4665008. Guy’s Hospital were able to supply policies from 2008 onwards: Written Statement of Keith Leakey para 4 WITN7124001. Liverpool University Hospital Foundation Trust was able to supply policies from 2004 but was not aware of documents predating that: Written Statement of Claire Alexander para 1 WITN7166001

1354 Written Statement of Christine Morris para 12 WITN7209001

1355 Written Statement of Christine Morris para 17 WITN7209001, NHS Foundation Trust Development and Management of Procedural Documents Policy 14 August 2020 WITN7209007

1356 Written Statement of David Burbridge para 3 WITN7143001

1357 Written Statement of Suzanne Rankin para 7 WITN4665008

1358 Written Statement of ANON paras 52-53 WITN0148001

Another man was unable to obtain a full set of medical records despite these being requested by his treating clinician. The man then made two formal complaints to the hospital, and was initially told that his records had been shredded because they related to the pre-1991 period. He was then told that his records were in fact in the hospital's archive on microfiche.<sup>1359</sup>

The onus that has frequently been placed on those who are infected and affected to request, correspond, chase and complain in order to access medical records has been weighty and unnecessary. It has caused a number of people to feel that the system is against them, and perhaps hiding things from them.

## Issues identified by NHS trusts, health boards and clinicians

From the sample of evidence the Inquiry has received from NHS trusts and health boards in the UK, and from clinicians, a number of themes can be identified in relation to the destruction and retention of medical records in addition to the application of retention policies.

Firstly, reorganisations within the NHS have resulted in a large number of records being destroyed. Alistair Tough, former archivist at Glasgow, states that following the creation of NHS trusts in 1993/94, there was widespread destruction of non-current clinical records, particularly those dating to the 1950s, 1960s and 1970s.<sup>1360</sup> A similar point is made by Louise Williams, archivist at the Lothian Health Services Archives.<sup>1361</sup> Suzanne Rankin, chief executive officer of Cardiff and Vale University Health Board, acknowledges that *"In the 1970s, documents stored at the Cardiff Royal Infirmary were moved to the University Hospital of Wales as part of the Health Board's restructuring. In this move, it is possible that some documents and records may have been lost or destroyed."*<sup>1362</sup>

Records were transferred to microfilm and microfiche from *"legacy organisations"*, that is hospitals that no longer operate in Northern Ireland, with hard copy documents being destroyed.<sup>1363</sup> There was a particularly complex process for the transfer of documents when the Royal Liverpool Hospital opened in 1978 and when the Royal and Broadgreen Hospitals amalgamated in 1995:

*"Prior to the opening of the Royal Liverpool Hospital (RLH), I understand that the closing hospitals in Liverpool were allocated a new RLH number to each convert their records to the same numbering system. This resulted in some patients having more than one number in the RLH ... The non-current records at the opening of the [RLH] which needed to be retained were microfilmed, and if a patient presented to the (new) RLH their microfilmed records were copied under their old case-note number and another volume of records was commenced. Once discharged, the*

1359 Written Statement of ANON paras 15-17 WITN1889001. For the response from Warrington Hospital, see Written Statement of Dr Alexander Crowe paras 84-99 WITN4198001

1360 Note from Alistair Tough regarding NHS Greater Glasgow and Clyde archiving systems 13 December 2019 para 3 WITN6911004

1361 Written Statement of Louise Williams para 1.9 WITN4690001

1362 Written Statement of Suzanne Rankin para 18 WITN4665008

1363 Written Statement of Caroline Leonard paras 2.5-2.8 WITN3449095



*record was then microfilmed and then filed behind the first volume microfilm, then second volume etc. The Royal and Broadgreen Hospitals amalgamated in 1995 and it is understood that the same process was followed.”*<sup>1364</sup>

Secondly, records management in some locations was previously managed locally by services, for example in Glasgow<sup>1365</sup> and Belfast,<sup>1366</sup> resulting in different practices in respect of both the destruction and the recording of the destruction of documents, leading to further uncertainty about what has happened to records. In addition, the local management of records means that there may be multiple locations where records are held in separate repositories, and where transfer from localised to centralised records management has taken place then documentation may be limited as to what was and was not transferred.<sup>1367</sup>

Thirdly, the changes from paper records to electronic records, sometimes via microfiche, have also caused some losses. In Swansea, Dr Saad Al-Ismael, consultant haematologist from June 1982 to February 2018, explained that:

*“up to 1980, all the blood transfusion documents, that is blood and blood products on part of haemophiliacs, were actually paper documents, and they were since, being many years, been lost. Then between 1980 and 1984 we acquired the computer system called TelePath, and -- oh, maybe before that we acquired a computer system. Anyway, so, at 1985 that was changed. It may be changed to TelePath, and we were told that the previous computer system we -- would be microfiched and stored. And -- but that actually -- it was microfiched but it was unrecoverable, I was told by the head of blood transfusion, when the first request from the Infected Blood Inquiry came to the Chief Executive. In 1985 to [1991] was TelePath, and this is the one which was microfiched. And then after 1991 until 2003 we changed to another system, called ACT, and when that laboratory system moved to another system called MasterLab, in 2003, all the documents were transferring to MasterLab. So anything really which was in TelePath -- if you like, you would not be able to get any documentation after 1991 from our computer system, unfortunately.”*<sup>1368</sup>

Fourthly, different names of patients have caused difficulties, as have patients being seen in multiple departments. In Belfast *“In a number of other instances, it emerged that ‘known’ names or middle names had been used to register patients, rather than the patient’s actual forename.”*<sup>1369</sup> This is an experience mirrored by the evidence of those infected and bereaved family members who have struggled to find records because of name changes and spelling errors in names. David Armstrong, professor of medicine and sociology at King’s College London, highlighted that patients were meant to have one set of notes but when they were

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1364 Written Statement of Claire Alexander para 3 WITN7166001

1365 Written Statement of Iain Paterson para 4 WITN6911007

1366 Written Statement of Caroline Leonard para 1.6.2 WITN3449001

1367 Written Statement of Caroline Leonard para 1.6.2 WITN3449001

1368 Dr Saad Al-Ismael Transcript 17 November 2020 pp149-150 INQY1000074

1369 Written Statement of Caroline Leonard para 1.6.2 WITN3449001

seen in different departments there would be *“lots of sets of notes that were circulating in the hospital under these different consultants and, now and again, an attempt would be [made] to pull them all together into a unified system, but it depends on how many visits the patient was making ... it became very, very difficult to carry through those notes to follow the patient.”*<sup>1370</sup>

Fifthly, in many haemophilia centres, patient records were kept separately to the main hospital records. Dr Gerard Dolan, consultant haematologist at the Queen’s Square Medical Centre, Nottingham, from 1991 until 2015, has told the Inquiry that when he arrived at Nottingham *“there had been a significant issue with case records”* and *“some consultations were recorded on discrete hospital out patient paper and some of these did not get filed.”*<sup>1371</sup> The use of separate records was partly pragmatic to ensure easy access should a patient attend a haemophilia centre during the night. In addition, Professor Gordon Lowe of Glasgow Royal Infirmary told the Inquiry:

*“every patient had case records, obviously. For a severe haemophiliac, these could become several volumes, several feet high, over the years from the number of submissions that they had. And we always wanted to keep all the records available in the haemophilia unit. Now, as you know, records can be destroyed at intervals by managers and records departments just wanting to keep their shelves clear, but there was a general recommendation by the UK Genetic Disorder Society, or whatever it was called -- I can’t remember -- that it was preferable that these records not be destroyed. And there was a very good reason for that in patients with haemophilia because, as you will know, it’s transmitted by female carriers, and it skips generations. So if a patient, say, dies and the records department say, ‘Well, that’s that’, and destroy the records, the problem is that 40 years later some granddaughter becomes pregnant and wants to know if she is a carrier and what kind of haemophilia was it. So in general we tried to keep all the records in the haemophilia centre, and the number [of] filing cabinets increased from about I think one, when I arrived in 1975 -- at last count I think it’s about 20 filing cabinets.*

*If a patient died, we would put [the records] in a locked cupboard within the haemophilia centre, because we occasionally had the problem that the records department said seven years, or whatever is the current policy, and would destroy them. So we tried to retain them as much as we could. But, in practical terms, we had a small folder in the unit, as I think many other centres did, which listed the basic details of the patient and what treatment they were on and information like the family tree and the UKHCDO [UK Haemophilia Centre Doctors’ Organisation] registration number, so that if a patient turned up in the middle of the night and for some reason the case sheets had gone missing, they had attended another*

1370 Professor David Armstrong Transcript 14 September 2022 p116 INQY1000240. Professor Armstrong is a member of the Inquiry’s Public Health and Administration expert group.

1371 Written Statement of Dr Gerard Dolan para 10 WITN4031001

*clinic, they had gone to a [surgical] ward for operation, we had the essential information that was needed to know what kind of haemophilia it was and what the treatment would be.”<sup>1372</sup>*

Similarly, Dr Al-Ismaïl stated that prior to the proper establishment of the Swansea Haemophilia Centre medical records “*would have been in the general records [and] would not be in the haematology department. It’s only when we moved to Singleton that we kept the haemophiliac notes in the Haematology Department.*”<sup>1373</sup>

Moreover, some HIV-positive patients treated in haemophilia centres had parts of their records kept separately to their haemophilia records. For example in Cardiff, Professor Peter Collins stated that when an audit of medical records was undertaken:

*“the only key documents that were missing which came up in the audit by Dr Hill was that the people’s HIV results were filed -- they were all filed together, separate from the notes. As far as I’m aware, those are the only key documents that were not in the notes that one would have expected to be in the notes. When I arrived in Cardiff, all of the notes of the people who had died of HIV were in a cupboard in the office that I inherited and we have kept those notes ever since.”<sup>1374</sup>*

In addition, a number of patients treated by Professor Christopher Ludlam have raised concerns that Professor Ludlam kept a separate file regarding patients’ HIV/AIDS infections.<sup>1375</sup> Professor Ludlam has stated that:

*“For those patients who were anti-HTLVIII positive I kept short ‘thumbnail’ sketches of pertinent clinical information along with laboratory findings ... I kept a small number of notes (no more than a single sheet of paper for each patient) separate from the main hospital case records in relation to people with haemophilia who came to see me early in 1985 in response to the December 1984 meeting, the circular letter written to all patients and the encouragement of the haemophilia staff to inquire about their anti-HTLVIII status. These notes were kept separate because as a team we decided at this time that we would not make any record related to HTLVIII or AIDS in the patients’ notes because of discrimination against positive patients even within the hospital.”<sup>1376</sup>*

The multiplicity of locations for the storage of records inevitably increased the difficulties in obtaining records and identifying whether or not they had been destroyed.

Finally, some individuals have simply been unable to establish what has happened to their records – there has been no explanation of what has happened to them or where they might

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1372 Professor Gordon Lowe Transcript 9 December 2020 pp26-28 INQY1000083. Professor Lowe became co-director of the haemophilia centre at the Glasgow Royal Infirmary in 1988.

1373 Dr Saad Al-Ismaïl Transcript 17 November 2020 p138 INQY1000074, Written Statement of Dr Saad Al-Ismaïl para 181 WITN3761005

1374 Professor Peter Collins Transcript 15 January 2021 pp85-87 INQY1000089

1375 See for example Written Statement of Robert Mackie paras 13-15 WITN2190001

1376 Written Statement of Professor Christopher Ludlam paras 110-111 WITN3428027

be. For example, Derek Harrell obtained a record from his GP confirming his admission to and discharge from hospital to undergo a procedure on his nose in August 1981 at the Queen Mary’s Hospital in Roehampton. However, when he attempted to obtain a complete set of his medical records, he received a letter stating that “*despite extensive searches we have been unable to trace your medical records relating to your stay here in 1981.*”<sup>1377</sup> Rosamund Cooper was treated at the Manchester Children’s Hospital, the Manchester Royal Infirmary, the Withington Hospital and the Queen Elizabeth Hospital, Birmingham. After being diagnosed with Hepatitis C, she wanted to identify when she was tested for it so she tried to get copies of her records from the Manchester Children’s Hospital with the help of her specialist nurse. “*However, having said, ‘yes, no problem, leave it with me,’ she then rang us back to say my notes had, ‘gone down a black hole’ and she could not understand it.*”<sup>1378</sup>

## Environmental destruction

Environmental factors have been put forward on a number of occasions as an explanation for unavailability of records. It is clear that there have been a series of environmental incidents on some hospital, or record storage, sites over the years.

For example:

- A flood at Guy’s and St Thomas’ Hospital in 1998/1999 and a leak/flood in 2008 in an old portacabin.<sup>1379</sup>
- A fire due to arson at the site of (the then defunct) Sharoe Green Hospital in Lancashire on 24 July 2005 in which 87% of the medical records being held and stored on the site were destroyed.<sup>1380</sup>
- A fire on 12 July 2006 at an Iron Mountain storage unit in Bow, East London, which destroyed records from the Chelsea and Westminster Healthcare NHS Trust. Some 242,000 Trust medical records for the period of 1999 to 2004 and those relating to deceased patients were destroyed along with 36,000 patient therapy files and boxes of clinical risk paperwork.<sup>1381</sup>
- A flood of the basement at Chelsea and Westminster Hospital in around 2018 arising from a leaking pipe or the installation of the sprinkler system. The basement contained microfilms of records from the hospital, and “*several other closed hospitals in West*

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1377 Written Statement of Derek Harrell paras 106-107 WITN0943001, Letter from Maggie Brennan to Derek Harrell 3 December 2015 WITN0943004

1378 Written Statement of Rosamund Cooper para 13 WITN1168001, Rosamund Cooper Transcript 18 October 2019 pp95-97 INQY1000044

1379 Written Statement of Keith Leakey paras 8-9 WITN7124001

1380 Written Statement of Christine Morris paras 4-10 WITN7209001

1381 Written Statement of Dr Roger Chinn paras 5-17 WITN7266001

*London*". Twelve crates of records, six cardboard boxes and cabinets with microfilms and indexes were damaged in the flood.<sup>1382</sup>

- A flood in the Manchester Royal Infirmary in September 2008.<sup>1383</sup>
- A fire in the Blood Transfusion Laboratory at the Trafford General Hospital in 1993 which resulted in all paper records on that site being destroyed.<sup>1384</sup>

However, it is also clear that while some infected individuals and their affected family members have been told that records have been destroyed due to environmental incidents, some trusts or health boards are now unable to confirm that this is what happened. For example, Edward Massey was treated at the Manchester Royal Infirmary during the 1960s to 1980s and applied for his medical records shortly after his diagnosis with Hepatitis C in 2005. He was told that most of his records: *"had been destroyed and that they had experienced a flood in the past. I also applied to Lancashire and South Cumbria Agency for my medical records and was informed they had also been destroyed."*<sup>1385</sup> The Trust has been unable to confirm the existence of a flood: *"Despite enquiries made with Manchester Royal Infirmary (MRI)'s senior management team, Clinical Governance team, Estates & Facilities team, Subject Access Request team and Medical Records team, we have been unable to verify whether such an event occurred. This is due to the passage of time since the alleged event and the present day."*<sup>1386</sup>

Nevertheless, one long-standing staff member could recall *"a series of floods at MRI that affected the medical records library, which used to be in the basement"*. However, *"due to the passage of time, this member of staff cannot recall exactly when the floods occurred but does believe they were around the time in question (mid-1980s)."*<sup>1387</sup> The Trust confirmed that no records – either patient case notes or other records that would reference a flood – exist from that time because of the Trust policy on retention, which means that these records have been destroyed.<sup>1388</sup>

There are numerous other examples of an individual being told, often verbally, about an environmental incident destroying records but the Trust has been unable to find any documentation about it.<sup>1389</sup> Whereas in other contexts such an absence might suggest that the postulated event never actually happened, in the case of medical records it cannot be taken as evidence that a patient's memory is wrong. Incomplete though it may be, it is often

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1382 Written Statement of Dr Roger Chinn paras 18-23 WITN7266001

1383 Written Statement of Professor Jane Eddleston para 5 WITN7041001

1384 Written Statement of Professor Jane Eddleston para 5 WITN7041001

1385 Written Statement of Edward Massey para 17 WITN1929001

1386 Written Statement of Professor Jane Eddleston para 7 WITN7041098

1387 Written Statement of Professor Jane Eddleston para 9 WITN7041098

1388 Written Statement of Professor Jane Eddleston para 8 WITN7041098

1389 See for example Written Statement of Daniel Stocks para 4 WITN0458001, Written Statement of David Burbridge para 8 WITN7143001, Written Statement of Craig Tansley paras 67-68 WITN1555001, Written Statement of Paul Brooks para 1 WITN7164001, Written Statement of Richard Titheridge paras 8.3-8.7 WITN0252001, Written Statement of Breda Kavanagh para 1 WITN7113001

the only evidence there is to resolve any question about the patient's treatment or infective status. It may be hearsay, but if there is no evidence to the contrary it will be sufficient proof.

Alasdair Cameron who was infected with Hepatitis C from a blood transfusion during an ileostomy, states that:

*“There are unfortunately no medical records available from the time of my operation. I am aware from Sheila’s line of work [his wife is a retired consultant clinical scientist in virology] that medical records were poorly stored in Scotland in the 1970s, with mould and water damage not being uncommon. The staff in the Gastroenterology department on Level 7 of Gartnavel did unsuccessfully make enquiries in an attempt to discover any medical records from the time and believe they were routinely destroyed after a set period.”*<sup>1390</sup>

Richard Titheridge’s wife was infected with HIV through blood transfusions during surgeries for ulcerative colitis and septicaemia in 1984 and 1985. When she was diagnosed in 2003, Dr Patricia Hewitt attempted to trace the records of the transfusions on behalf of the National Blood Service and the hospital located microfilmed medical notes. Richard then tried to access her records in 2007 and was told they had been destroyed in a sewage leak before 2003. He tried again, and explained that the records had been accessed on microfiche in 2003. The response was then that medical records were routinely destroyed after 15 years. His MP also tried to assist but did not succeed in accessing the records. Richard reflected: *“She was the first person to have a Caesarean section and total colectomy at the same time. Her consultant even asked her to speak to his students in an auditorium because she was such an important case. Why would you destroy those records?”*<sup>1391</sup> The healthcare trust told the Inquiry that they had made attempts to locate information about a sewage leak and that whilst it appeared that a flood may have occurred, corporate records were only retained for seven to ten years and therefore no information was available.<sup>1392</sup>

The lack of a record of such environmental incidents is often because there has been no historic requirement, either nationally or as part of individual trust or health board policies, to record and evidence environmental destruction of medical records. Sometimes it is because the documents recording such incidents have themselves been destroyed under retention policies.<sup>1393</sup>

## Concerns relating to the quality and content of medical records

A number of concerns have been raised about the quality and content of medical records when records have been obtained by individuals. In particular, concerns relate to inconsistency

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1390 Written Statement of Alasdair Cameron para 5 WITN0090001

1391 Written Statement of Richard Titheridge paras 8.3-8.7 WITN0252001, Letter from National Blood Service to Dr A J France 8 October 2003 WITN0252002

1392 Written Statement of Breda Kavanagh WITN7113001

1393 Written Statement of Emile Armour para 1 WITN7140001

between what is recorded in the notes and the information that was given, or not given, to a patient; and inaccurate information being recorded in the records.

The Inquiry has heard substantial evidence about the differences between what individuals recall being told, or not told, orally and what is recorded in their medical records. This is discussed further in the chapter on *People's Experiences*. However, in addition, there are examples of matters recorded in medical records which simply have been wrong. For example, a man suffered a traumatic operation as a child and received a blood transfusion and blood products. He was later diagnosed with Hepatitis C and describes finding out that his medical records contained “*many falsehoods*” such as that he was “*married; had two kids; false teeth and was an intravenous drug user!*” He states that his request that these references be “*expunged*” from his records was granted in 2007.<sup>1394</sup> A widow whose husband died in 2013, has found an entry in his records dated 11 December 1981, which set out a “*Flare up of symptoms*” around two weeks after he received NHS concentrate. However, an identical entry is recorded in her father-in-law’s medical records. The two men shared the same name.<sup>1395</sup> In her oral evidence to the Inquiry the witness put it in these terms: “*How can you have two separate patients with exactly the same comments? That’s my question.*” She further stated: “*It looks like this entry has been cut and paste like a piece of paper over the top of it which concerns me too because I didn’t get the originals, I had scans. So I couldn’t look and investigate that any further.*”<sup>1396</sup>

Valerie White’s son Martin was diagnosed with HIV as a teenager after receiving infected Factor 8. She sought his medical records:

*“There are absolutely no notes in Martin’s medical records to say that he was being tested, when he was being tested, when he was diagnosed, or when we were informed of his infections. It seems as though one minute he was normal and the next minute his notes report that he was HIV positive. When I applied for them, I had hoped that Martin’s medical records would clarify what had happened to Martin for me, but to my disappointment, they did not.”*<sup>1397</sup>

The accuracy, or otherwise, of references to alcohol use has been of particular concern for very many witnesses, particularly for those with Hepatitis C. There were numerous examples in the evidence of this<sup>1398</sup> including Annette Hill-Stewart, whose husband died in 2013 and in whose medical records there were references to his alcohol intake, who said:

*“I was horrified when I read that. I have never, ever seen Angus with a beer in his hand, a spirit in his hand. We have -- he was not a pub visitor. He hated pubs,*

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1394 Written Statement of ANON para 34 WITN1899001

1395 Written Statement of Annette Hill-Stewart para 10 WITN1001001, Patient medical note for Angus Stewart WITN1001004

1396 Annette Hill-Stewart Transcript 9 October 2019 pp112-113 INQY1000038

1397 Written Statement of Valerie White para 22 WITN1725001

1398 For example Written Statement of Patricia O’Shea para 4 WITN3731001, Written Statement of ANON para 11 WITN2026001, Written Statement of Pauline Major paras 14-15 WITN0511001, Written Statement of Susan Delglyn paras 30-33 WITN1183001

*wine bars, nightclubs, and indeed when we used to go on holiday we would frequently fall out because I would want to go to something special after and he would be adamant, 'No, we're going back to the room by 10.30', and there we would be in the most exotic location and he wanted to go back to the room. In the whole time that I knew Angus he would like a glass of wine, we'd cook together and have a glass of wine and go out for meals and have a glass of wine but he was not the type of person that would go out drinking, not at all."*<sup>1399</sup>

Ruth Spellman, whose late husband Bill was infected with Hepatitis C through blood transfusions, says: *"I am really quite shocked at the mention of excessive alcohol in Bill's medical notes as it does not sound true to me. I lived with Bill for 30 years and I never recall him drinking to such levels. I do not see how it is possible that Bill was recorded as alcohol dependant and do not know whether he ever had the opportunity to review his notes. He was doing a very responsible job and we had three young children."*<sup>1400</sup>

Gideon Bullock's father Kenneth died from Hepatitis C. He described his last days as *"unbearable to witness"* but *"In the wake of his death, we had no idea of the story which was about to unfold, and only a few weeks after his death, we discovered the misdirection."*<sup>1401</sup> The GP records showed he had been diagnosed with non-A non-B Hepatitis in 1983 *"in view of his exposure to blood products"*<sup>1402</sup> but *"this diagnosis was the first and last mention of contaminated blood. Every single report and update on the state of his health by the St. Thomas' clinical team at The Haemophilia Centre over that 16 years stated acute alcoholism as the cause of his liver disease."* Not knowing that his mother had obtained the GP records, St Thomas' told them: *"At no time has Guy's and St. Thomas' suggested that Mr Bullock was an Alcoholic."*<sup>1403</sup> Guy's and St Thomas' NHS Trust did not offer a response when contacted by the Inquiry. In April 2017, in his last speech in Parliament,<sup>1404</sup> Andy Burnham MP read from a letter Hazel Bullock, Kenneth's wife, had written about her husband: *"he was refused a liver transplant ... and left to die still unaware of these appalling accusations. He did not drink alcohol ... My husband died completely unaware of these accusations that have shocked family, friends and colleagues alike."*<sup>1405</sup>

Doctors have generally responded to such criticism by defending their records as being an accurate representation of what they were told.<sup>1406</sup>

As a final note on the contents of medical records, it is not uncommon that the author of a record goes beyond matters of direct clinical relevance. They may express a personal

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1399 Annette Hill-Stewart Transcript 9 October 2019 pp118-119 INQY1000038

1400 Written Statement of Ruth Spellman para 28 WITN0179001

1401 Written Statement of Gideon Bullock para 8, para 13 WITN1731001

1402 Patient medical consultation note for Kenneth Bullock 11 October 1983 p2 WITN1731003

1403 Written Statement of Gideon Bullock para 8, para 16, para 18 WITN1731001

1404 Hansard parliamentary debate on Contaminated Blood 25 April 2017 RLIT0001578

1405 Hansard parliamentary debate on Contaminated Blood 25 April 2017 p4 RLIT0001578

1406 For example: Written Statement of Dr Joan Trowell para 8 WITN3740001, Written Statement of Dr Peter Hamilton paras 20-21 WITN4197001, Professor Gordon Lowe Transcript 11 December 2020 pp24-26 INQY1000085



view about the patient which has little to do with objective clinical observations, diagnosis or treatment. These may range beyond issues of the supposed alcoholism of a patient, to statements such as those of which Della Ryness-Hirsch complained (“*neurotic mother*”)<sup>1407</sup> which are gratuitous and have no proper place in the records.

Wayne Gathercole’s medical notes contain the observation that his infection with Hepatitis C “*seems to be more of a problem for Wayne’s mum than it is for Wayne*” and he recalls how his parents were talked down to and dismissed, particularly his mother when she questioned things.<sup>1408</sup> Such statements reveal attitudes of superiority which should have no place in what should, in principle, be a process of partnership in ensuring good care for the patient.

## Gaps in records

The consequence of destruction policies is that where they are applied, only more recent documents may survive. The consequence of archiving documents in places which have been affected by environmental destruction is the same. Neither explains why there should be a gap between “old” records and “recent” records in which nothing is to be found. Yet it is this which a significant number of infected and affected people have reported. The reports are not all of the same kind. They are of missing records relating to particular procedures or appointments, to particular years or to particular types of record.

There are a number of examples:

- A man has no medical records relating to a period in hospital, which he recalls as being weeks rather than days, after a road traffic accident in 1978 when he required the insertion of a metal plate into his ankle.<sup>1409</sup>
- A woman whose late husband was infected with HIV and Hepatitis C as a result of treatment for severe haemophilia at the Royal Free Hospital describes there being no reference to her husband’s attendances at the hospital in February 1985 when he received his diagnosis of HIV. She recalls that he attended one appointment where he was told that he did not have AIDS and then he attended a week later to be told by Dr Peter Kernoff the opposite and that he was in fact infected. Neither appointment appears in his medical records.<sup>1410</sup>
- A man has two pages missing from his records relating to surgery in June 1984 at the North Middlesex Hospital (formerly the Prince of Wales Hospital) for a perforated duodenal ulcer: “*they are pages 20 and 21 of a set that I have received*”. After the procedure and his recovery in intensive care, he was told that the surgery had not gone well and that he had required multiple blood transfusions.<sup>1411</sup>

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1407 See the final section of this chapter. Written Statement of Della Ryness-Hirsch para 36 WITN0282001

1408 Written Statement of Wayne Gathercole para 11 WITN4003001

1409 Written Statement of ANON para 54 WITN2026001

1410 Written Statement of ANON paras 10-13 WITN1578001

1411 Written Statement of ANON para 3 WITN1967001

- The partner of a man who died in 2002 sought his records. In 1984, when he was 11 years old, his parents were told that he had contracted HIV through infected blood products. She described herself being “*initially optimistic when two substantial packages arrived*” after seeking his notes. She received in excess of 700 pages. However, the bulk of these are “*green cards*” and the medical records are incomplete, including a number of years between 1977 and 1991 (including 1983 and 1984) not featuring at all in the green cards.<sup>1412</sup>
- A father, whose son was infected with HIV and Hepatitis C, applied for his son’s records to appeal a negative decision from the Skipton Trust. The records arrived with only a single haematology letter from 1979 to 1988. All the other notes were provided, including paediatrics and orthopaedics but the haematology records were missing.<sup>1413</sup>

## Inaccuracy of UKHCDO records

People with bleeding disorders who have found gaps in their records have reviewed the data held about them on the UK Haemophilia Centre Doctors’ Organisation (“UKHCDO”)<sup>1414</sup> National Haemophilia Database to see if it would provide answers. However, it was collated over time from patient records<sup>1415</sup> and is riddled with inaccuracies despite the efforts of the UKHCDO. There are numerous examples including:

- One man states that his UKHCDO records are “*partial and incomplete*”. No batch numbers are recorded. Treatment data is missing between 1974 and 1980 and between 1989 and 1996. The results of his negative HIV tests are “*incomplete and inconsistent with medical records*”. There is no record of hepatitis tests and the Hepatitis C lookback data is inaccurate.<sup>1416</sup>
- Alan Burgess’ UKHCDO records lists the “*Date first positive*” as 15 January 1985 but he attended for testing in August 1985 and the sample date is listed as 15 September 1985. He does not know if that is a transcription error or there has been another test of which he is not aware.<sup>1417</sup>
- Graham Manning was treated with US Factor 9 concentrate in 1978 but this is not recorded in his notes; only his subsequent treatment with cryoprecipitate and NHS Factor 8 is recorded, and this was given after it was confirmed that he did not have a Factor 9 deficiency but a mild Factor 8 deficiency.<sup>1418</sup>

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1412 Written Statement of Rebecca Ward para 12 WITN0870001. Green cards were completed by the patient, parents and medical staff to record blood products administered.

1413 Written Statement of ANON para 58 WITN0995001

1414 In 1992 the UK Haemophilia Centre Directors’ Organisation became the UK Haemophilia Centre Doctors’ Organisation.

1415 Bleeding Disorders Statistics for the Infected Blood Inquiry 2022 p9 WITN3826016

1416 Written Statement of ANON paras 5-6 WITN1446001, Patient medical record for Anon 9 August 2019 WITN1446002

1417 Alan Burgess Transcript 28 October 2019 pp16-17 INQY1000045, Table showing Patient HIV data WITN1122018

1418 Graham Manning Transcript 7 June 2019 p70 INQY1000016

- A widow describes her husband’s UKHCDO records as “*farcical*”. The date of her husband’s first HIV diagnosis is listed as October 1985 whereas the ELISA<sup>1419</sup> test indicates this was August 1984. The UKHCDO record states that her husband was not seen in 2004 and 2005: “*Well, since he had been cremated for nearly seven years by then it’s hardly a surprise.*”<sup>1420</sup>

Clearly the UKHCDO records are only as good as the information provided to them by the treating hospital, which in turn is only as good as the record made by the clinician making the entry, and the person transmitting the data from the hospital to the UKHCDO. These serial opportunities for human error to play a part have resulted in significant inaccuracies in the records.

The possibility of human error did not stop when the data reached the UKHCDO. There also appear to have been difficulties in relation to the entering of the details into its database. Consequently, in a July 2019 letter a number of individuals were informed by Professor Charles Hay, director of the National Haemophilia Database, that medical records from paper archives had been missed out:

*“on recent inspection of the paper archive we discovered that some details, from paper forms submitted to the database in the seventies through to the nineties, were archived but not entered into the electronic record. These forms were submitted many years ago by your Haemophilia Centre when the database was held in Oxford before paper reporting was phased out in 2000 ... We apologise unreservedly that you were not sent all the information after your initial request and for any distress or difficulties this may have caused. Please be aware that some paperwork had other names on it in addition to yours, and therefore these parts of the records have been blacked out to preserve confidentiality.”*<sup>1421</sup>

## Significant interference in medical records

There are a handful of examples that raise serious issues of intentional interference in medical records. Unfortunately, due to the passage of time, it is difficult to reach any firm conclusions on what happened in these individual situations. Nevertheless, they do raise concerns that there may have been a closing of ranks in certain contexts with the result that someone thought it prudent to remove items from medical records.

Della Ryness-Hirsch has provided written and oral evidence to the Inquiry about her son Nick’s infection with Hepatitis C and his death in 2012. Nick was treated at Great Ormond Street Hospital (“GOSH”) from 1976 until 1985. He first received Factor 8 on 3 November 1980 due to a lack of availability of cryoprecipitate and notwithstanding his parents’

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1419 Enzyme-linked immunosorbent assay.

1420 Mrs AJ Transcript 11 October 2019 pp90-91 INQY1000040

1421 Letter from Professor Hay to Matthew Merry 22 July 2019 p2 WITN1389005. In response to this criticism being put to UKHCDO under the Inquiry Rules 2006, UKHCDO noted that all records are now digitised, a process that had taken two years to complete.

expressed concerns about the safety of American blood products. In 1985 GOSH wanted to switch his treatment to American Factor 8 and so his care moved to the Royal Free Hospital. His mother gives the following account:

*“We returned to GOSH the same day but they refused to give us the file with Nick’s medical notes. I don’t remember who it was at GOSH that refused to hand over his records. However, about 2 weeks later a nurse from Great Ormond Street rang me at work and said if we’d like to meet her she would give me Nick’s file. She met us in the street. Although I recognised her at the time I can’t remember her name now. I took the medical records to the Royal Free. I thought they were complete but I couldn’t have known for sure. I don’t remember looking through them until we got to the Royal Free as I thought it was the right thing to do. We looked at the notes with the head nurse of the haemophilia department at the Royal Free whose name was Christine Harrington. There was a dated page with tramlines scrawled across, within which was written in large letters, ‘neurotic mother’. I recognised that this entry was from the day I kicked up such a fuss about refusing to allow Nick to be given American factor VIII in early 1980.”*<sup>1422</sup>

After her son died, Della Ryness-Hirsch applied for his medical records but the “neurotic mother” note was missing. She states that she “rue[s] to this day that I wasn’t savvy and didn’t photocopy the notes.”<sup>1423</sup> She only received the records after:

*“a bit of a struggle but at least I managed to obtain them. It took several physical meetings over the course of a month to eventually obtain both sets of records. That is when I first realised entries were missing. I have not been able to trace any testing for hepatitis or HIV within the GOSH records however, within the Royal Free records it is very apparent that Nick was regularly tested for both.”*<sup>1424</sup>

Paul Sartain was infected with Hepatitis B and Hepatitis C and recalls attending an appointment in the 1990s and reading a letter from a pharmaceutical company offering to donate money to the hospital charity if their product was used: “it was clearly on display in my file and I remember reading it upside down across the desk during a clinic review.” However, when he received his records, he was unable to find that letter.<sup>1425</sup> The Royal United Hospitals Bath NHS Foundation Trust confirms that it has not been able to find a copy of this letter in the witness’ medical records.<sup>1426</sup> There are no further details that are available about the circumstances in which it was removed, but there is an obvious motive for its deliberate removal if that is what happened.

One woman who received a blood transfusion on 23 May 1986 states that she was told by the ward sister that she needed a transfusion during the early stages of labour due to

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1422 Written Statement of Della Ryness-Hirsch para 36 WITN0282001

1423 Written Statement of Della Ryness-Hirsch para 37 WITN0282001

1424 Written Statement of Della Ryness-Hirsch para 47 WITN0282001

1425 Written Statement of Paul Sartain para 95 WITN1013001

1426 Written Statement of Dr Bernie Marden para 5 WITN7225001

anaemia. She recalls that she had a cannula inserted and she was “hooked” up to blood and the transfusion was started. Her recollection is that the transfusion was then stopped by a nurse before it was finished and she was told she needed to go for an ultrasound. She was diagnosed with Hepatitis C in 2016.<sup>1427</sup> When she requested her medical records for the purpose of applying to the Skipton Fund she was told some of her medical records were missing:

*“There are no records for the day of my transfusion, 23rd May 1986. There are doctors notes for the 19th, 20th, 21st, 22nd May and then for 24th May until I was discharged. There are no nursing notes for any part of the admission. There is nothing in my records which confirms that I had a blood transfusion on 23rd May 1986, or that I had an ultrasound on that day.*

*The discharge letter from my hospital admission in 1986 is ticked to say that I did not have anaemia. It is this that worries me most; I feel that the reason that I needed a blood transfusion has been hidden. It is as if they distorted the truth to cover up what they were doing.”*<sup>1428</sup>

The witness made a complaint to the Trust and has explained that:

*“I actually went up to the hospital in person, went to the reception desk and asked them to bring somebody down from the office to hand them my complaint letter and all a sudden they instantly found everything, except for the notes.*

*It took, all in all, about ten months from initial request for them to supply me with notes that they said they’d got and a letter to say that they thought that, due to the timescale and the building moves, that any letters from that time, except for the ones that I got either side of that, had been destroyed or lost and they’ve never come up with the day of the 23rd.”*<sup>1429</sup>

In a letter, dated September 2017, the Trust has stated that a “thorough search and investigation” was undertaken to try and find “any additional and/or secondary filing which may contain information in respect of a blood transfusion” in May 1986. No documents were found.<sup>1430</sup> Therefore, the single day of records has not been identified.

## Commentary

There is considerable material to show that patient records were not well kept, and had not been well kept for years before the periods of central interest to the Inquiry. Professor Armstrong said in his evidence that despite attempts to bring structure and coherence to medical records, removing what was extraneous continued to be haphazard “Everywhere”.<sup>1431</sup>

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1427 Written Statement of ANON paras 3-23 WITN1921001

1428 Written Statement of ANON paras 69-70 WITN1921001

1429 Mrs D Transcript 10 May 2019 p86 INQY1000008

1430 Letter from NHS Foundation Trust discussing lack of evidence of blood transfusion September 2017 WITN1921002

1431 Professor David Armstrong Transcript 14 September 2022 pp123-126 INQY1000240

He gave evidence about the poor quality of records systems and their generally patchy application in practice.<sup>1432</sup>

Given the evidence of the general poor quality of records systems across the whole of the NHS in the UK, the likelihood is that in the majority of cases the reasons why records which ought, in line with retention policies, to be available have not been found are probably a mixture of incompetence, a lack of proper systems, and the problems inherent in keeping paper records – the changing of patient names and addresses, the closing of hospitals, the occasional environmental problems which have arisen in storage facilities, and the difficulties of linking hospital and GP records as well as the records from one hospital department with those in another.

That said, the possibility that there may have been occasions in the past when records may deliberately have been left incomplete or have been filleted remains. There is clear evidence that on at least one occasion a patient has been deliberately tricked into having an unwelcome transfusion in circumstances in which at least some other health professionals have been complicit.<sup>1433</sup> Compared to deception like that, the filleting of records by some health professionals in respect of blood-borne infections would be much less difficult to achieve, may involve no other health professionals, and is thus perhaps easier to contemplate as having happened.

It has been the more recent need of many people, so as to secure registration with support funds, to first be provided with their historical medical records that has brought to light more examples of missing records.

Two particular series of allegations require particular examination. First, there are reports that there are some records missing which should be there – and these may also form a missing sequence in records which otherwise appear complete. Yet those missing parts are to the mind of the patient the critical periods for them being able to establish that their memories are accurate. Second, a number of litigants in the HIV litigation of the late 1980s and early 1990s report that the records of the critical period of their treatment can no longer be found.

Since the effects of general poor record-keeping, described above, would be expected to be random as between patients, times, and conditions, and these reports suggest something which instead of being random is linked to the particular patients, times, and conditions, there is reason to wonder so far as people with bleeding disorders are concerned if there is some feature linked to this litigation which is part of the explanation. Though this is a possibility, there is no documentary or oral evidence which suggests that records were legitimately removed because they had a part to play in the litigation and were never returned. It is to be expected that some hint of this would be documented. It does not seem to be the case. This reason must therefore be given only very limited weight. It can largely be discounted.

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1432 Professor David Armstrong Transcript 14 September 2022 INQY1000240

1433 Written Statement of Lesley McEvoy paras 6-7 WITN1934001. See the chapter on *Document Destruction*.

In short, if there is a link between the litigation and a gap in the records, this is not for an acceptable reason.

Given the evidence of Professor Lowe, and the credibility of two points he makes – about the size and number of files accumulated by many people with haemophilia, and the need to have swift access at any time of the day or night if urgent treatment is needed – it seems likely that in a number of haemophilia centres there was a good reason to extract recent records specific to treatment for haemophilia from the patient files, and keep them ready to hand in the centre. However, if extracted for this purpose, such files should have been returned to their parent files afterwards.

It approaches probability that on some occasions, and in respect of some patients when the fear of AIDS was at its height, and clinicians were scared of the stigma, abuse and even physical attack some of their patients might suffer, details in hospital records which related to HIV infection or treatment were removed. The purpose of this would be concealment of the facts – but the purpose would have been to protect the patient. The records removed may have been stored where fewer people had access to them, where they would have stayed and because, once there, no-one thought to repatriate them with the main records they have then remained missing from those records.

If it happened that records were extracted in this way to protect a patient's confidentiality, it should first have been discussed with the patient – but the evidence is persuasive that on very many occasions clinicians thought themselves entitled to take decisions about a patient for that patient. Whether that happened in any particular given case may well now be lost in the passage of time.

It also is not unreasonable to suppose that documents specific to haemophilia – testing, treatment, infection, research and diagnosis – which had been extracted from general storage in a hospital to be located at the haemophilia centre for the convenient efficiency of the centre may not have been repatriated to their parent files. The reasons for not being scrupulous about repatriation may have been a mixture of pressure of time, embarrassment that treatment at the centre had led to causing disease, worry about litigation, concern that gaps between test results and delivery of diagnosis might be too long, and a sense that the fewer people knew about a particular case of AIDS or hepatitis the better. Of these possibilities, only pressure of time comes close to being acceptable as a reason for not reuniting extracted records with their parent files in due course: the others are not.

If documents were selectively removed from files (and not returned) for any of the reasons just explored, they may not have been intended for destruction. However, such is the extent of the evidence that document retention was badly managed that it seems likely that over time these documents have in one way or another become irretrievable.

Though there are the reasonable possibilities discussed above, there is in general no way now of knowing in any individual case if it occurred, or whether records which are missing have been destroyed because it was thought to be policy to do so, or because there has been a failure of storage facilities to keep them safe and secure from flood, fire, pest or

other inadvertent destruction. Or because there have been individual or concerted attempts to remove them in order to protect clinicians who may have felt they had failed their patients and wished to hide the evidence of that.

I have already commented upon the disappearance from Department of Health files of significant material relevant to parts of the litigation, and concluded that some documents were deliberately destroyed in the Department of Health. However, it would not be right to conclude that this sheds any light on what happened to individual medical records.<sup>1434</sup>

In summary, there are reasons for concern. The passage of time and the incomplete nature of the available evidence means that it is not possible to reach firm conclusions in any individual case. Although there is suspicion that some health authorities or individuals reacted in a similar manner to what was happening around them, by hiding, removing or destroying some records that might be an embarrassment, there is insufficient evidence to conclude that a finding to this effect is justified across the board. I have, though, noted that the retiring Parliamentary and Health Service Ombudsman, Rob Behrens, was reported as recently as 17 March 2024 as describing part of his experience over the last seven years as *“having to confront a cover-up culture [within the NHS], including the altering of care plans and the disappearance of crucial documents after patients have died and robust denial in the face of documentary evidence”*. He plainly had in mind cases the facts of which are not, as they are in this Inquiry, difficult to be more certain about because of the passage of time and the fading of memories. His words add strength to the reasons for concern about what may have happened in the case of infected blood and blood products.<sup>1435</sup>

The best way, perhaps, of summing up what the Inquiry has heard is that expressed by those infected and affected represented by Thompsons’ solicitors in their closing submissions to the Inquiry:

*“The Inquiry has heard copious evidence about problems [that] have been experienced by patients/ parents/ patient representatives across the country in accessing medical records. This has had the effect of limiting the ability of patients or their relatives to gain a proper understanding of what happened to them or their loved ones. In many cases, missing or incomplete medical records have created a justifiable sense of injustice or, in many instances, suspicion about the fraudulent removal, destruction or concealment of records.”*<sup>1436</sup>

As they put it, it is to be expected in these circumstances that many have suspicions. In that sense, their feelings of suspicion are justified: but because so many years have passed, and because the reasons for the loss or disappearance of records are so difficult to establish, it is not possible to reach any firm conclusions as to how well-founded those suspicions are.

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1434 See the chapter on *Document Destruction*.

1435 The Guardian *NHS ombudsman Rob Behrens: ‘There are serious issues of concern’* 17 March 2024 p1 RLIT0002366

1436 Written submissions on behalf of the core participant clients represented by Thompsons Scotland 16 December 2022 pp1202-1203 SUBS0000064



What lessons are to be learned from this? On any view the destruction and disappearance of medical records has caused significant harm to individuals. This is its main effect. But it has also resulted in a loss of trust that is harmful both to patients and to the NHS more widely. It is critical to the future of the NHS that patients can generally trust what they are told, and trust that the NHS has their best interests at heart. Keeping accurate and complete records, and making them available on request, demonstrates the openness, transparency and rigour which patients and those close to them associate with a careful, caring system of healthcare. This has been sacrificed in the present case, such that patients have lost the trust they should have. It probably happened because good record-keeping was not given the status it requires. It will happen again if this does not improve. Steps must be taken to ensure it does not.

The same problem of poor quality record-keeping, and of the accessibility of data from them for purposes where that data can be kept anonymous, has been highlighted in the evidence of Professor Mark Bellamy, Professor James Neuberger and Dr Alison Cave (respectively the current chairs of the Serious Hazards of Transfusion Scheme, the Advisory Committee on the Safety of Blood, Tissues and Organs and chief safety officer of the Medicines and Healthcare products Regulatory Agency) that there has been a large level of under-reporting, so that data important for public safety is never recorded in any document or on any system even before questions of its retention or destruction arise.<sup>1437</sup> Professor Bellamy observed that: *“For example, in the Trust where I work, blood transfusion does not feature in the electronic patient record. It is still prescribed, administered and recorded on paper, which then sort of disappears into some giant library somewhere and, in theory, gets scanned and put on the system.”*<sup>1438</sup>

For the future, there are clear advantages to the use of electronic records over paper records and a transition to such records is continuing across many NHS trusts and health boards.<sup>1439</sup> Although the process of moving to electronic records has resulted in some loss of records, there are considerable advantages over paper records including protection from physical deterioration of the records and providing audit trails for amendments and deletions of and within records. Difficulties remain however in relation to the integration and interoperability of records between hospitals and GPs and across different services within the NHS.<sup>1440</sup> Entry into the records, and maintaining the systems, still depends on human action. These are both points of vulnerability. Those involved (almost all health professionals) should be clear that any failure of record-keeping is likely to result in some loss of trust in the system they serve. The accuracy of their work is important. So too is ensuring that what ought to be

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1437 Professor James Neuberger, Professor Mark Bellamy and Dr Alison Cave Transcript 16 November 2022 pp64-65, p84, pp89-90, pp91-93 INQY1000263. See the chapter on *Blood Transfusion: Clinical Practice*.

1438 Professor Mark Bellamy Transcript 16 November 2022 p93 INQY1000263

1439 For a discussion of the issues see: Written Statement of Dan West WITN7638001, Written Statement of Philip Bowen WITN7640001, Written Statement of Jonathan Cameron WITN7649001, Written Statement of Vinod Diwakar WITN7668001

1440 Professor David Armstrong Transcript 14 September 2022 pp164-165 INQY1000240. Dr Cave observed: *“I think we are some way off having a UK-wide linkage of primary [GP] and secondary [hospital] care.”* Dr Alison Cave Transcript 16 November 2022 pp95-96 INQY1000263

recorded actually is. If an electronic record is to be produced, it may be assumed too readily at present that it contains all the important information about the patient's past care that might be necessary for the future management of their care: it is plain that some matters which ought to be recorded may not be, those that are may not be accurate, and that the reader of those records may have to inquire as to whether there are any other records "out there" which may be relevant but are missing.

## 6.11 National Support Schemes

This chapter looks at how the need for reform of the Alliance House Organisations gave rise to four national support schemes. It considers how these national support schemes operated and the impact of the disparities between them.

### Key Dates

**2013** the Government considers reform of the AHOs.

**November 2014** Prime Minister agrees to wait for the release of the Penrose Report before consultations on reform proceed.

**January 2015** APPG publishes a report on the AHOs.

**March 2015** the Penrose Report is published and the Prime Minister announces consultation into the reform of the AHOs and pledges up to £25 million in support.

**March 2015** statement on behalf of the Scottish Government committing to review the existing schemes.

**December 2015** Financial Review Group publishes proposals for changes to financial support in Scotland.

**January 2016** Department of Health launches consultation on reform of AHOs.

**March 2016** Scottish Government decides to establish a new Scottish scheme.

**July 2016** Department of Health publishes response to the consultation and announces decision to have a single scheme administrator in England.

**April 2017** SIBSS becomes operational.

**November 2017** EIBSS, WIBSS and IBPS (NI) become operational.

**December 2018** Scotland introduces self-declaration regarding impact of Hepatitis C

**April 2019** Prime Minister announces additional funding for EIBSS.

**January - August 2020** announcements of reforms to IBPS (NI).

**March 2021** the Government announces changes to the schemes to address disparities.

### People

**Jane Ellison** Parliamentary Under-Secretary for Health (2013 - 2016)

**Vaughan Gething** Minister for Health and Social Services, Wales (2016 - 2021)

**Jeremy Hunt** Secretary of State for Health and Social Care (2012 - 2018)

**Penny Mordaunt** Paymaster General (2020 - 2021)

**Shona Robison** Cabinet Secretary for Health, Wellbeing and Sport, Scotland (2016 - 2018)

**Anna Soubry** Parliamentary Under-Secretary of State for Public Health (2012 - 2013)

**Robin Swann** Health Minister, Northern Ireland (2020 - 2022, 2024 - present)

### Abbreviations

**AHOs** Alliance House Organisations

**APPG** All-Party Parliamentary Group

**EIBSS** England Infected Blood Support Scheme

**IBPS (NI)** Infected Blood Payment Scheme for Northern Ireland

**SIBSS** Scottish Infected Blood Support Scheme

**WIBSS** Wales Infected Blood Support Scheme

## The need for reform

Dissatisfaction with the Alliance House Organisations (“AHOs”) increased during the 2000s. Many of the problems identified in the previous chapters were being brought to the attention of politicians by their constituents. By 2013 reform began to be considered by ministers. Anna Soubry was by then Parliamentary Under-Secretary of State for Public Health. She attended a meeting at the House of Commons with the All-Party Parliamentary Group (“APPG”) and a number of campaigners on 17 April that year. Problems with the way people were treated by the AHOs were raised at the meeting. Anna Soubry *“confirmed she had spoken to the various funds to make clear it is not acceptable and changes are happening. But she has major concerns over the set-up of some funds and the fact there are so many and the bureaucracy that makes people feel they are begging and beholden”*; she expressed exasperation about the time it took *“to sort anything out”*; and heard that *“the systems set up by successive Governments are divisive and people are being dealt with in an uncompassionate and ineffective way.”*<sup>1441</sup> She told the Inquiry that when briefed about the schemes she *“could not understand why there were different funds or why they were so complicated and difficult for applicants to access. It struck me as illogical and profoundly wrong”* and that *“the ‘cap in hand’ nature of it was humiliating for the beneficiaries.”*<sup>1442</sup>

Anna Soubry then asked her officials to provide her with options for reforming the Hepatitis C payments system, although her recollection was that there was little political will to change the system.<sup>1443</sup> Jane Ellison succeeded Anna Soubry in her ministerial role in October 2013, and also sought advice on options for reform.<sup>1444</sup> It plainly came to the ears of David Cameron as Prime Minister, and when during the next month he met a group of people accompanied by Alistair Burt MP he came to believe *“the system was not fit for purpose.”*<sup>1445</sup> The meeting made the shortcomings *“even plainer”*.<sup>1446</sup>

A submission to Jane Ellison and to the Secretary of State for Health, Jeremy Hunt, in January 2014 suggested that there was no additional money available for reform and that *“we will need to consider what might be done to reform the current system to address the key concerns of campaigners and MPs, within the current, or lower, budget envelope of the system.”*<sup>1447</sup> The submission noted that the payment levels under the existing system were *“for the most part arbitrary, and, with some exceptions, not based on any assessment of impact or need.”*<sup>1448</sup>

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1441 Minutes of APPG on Haemophilia and Contaminated Blood meeting 17 April 2013 p3 WITN1056131

1442 Written Statement of Anna Soubry para 12.1, para 15.1 WITN6662001

1443 Written Statement of Anna Soubry para 15.1 WITN6662001, Options for Review of the Contaminated Blood Payment Schemes p2 DHSC5143634 and a further options paper dated 11 July 2013. Memo from Ben Cole to PS(PH) and the Secretary of State 11 July 2013 WITN3499010. The first options paper used the terminology of people having been *“inadvertently infected”*, discussed in the chapter *Lines to Take*.

1444 Memo from Ben Cole to PS(PH) and the Secretary of State 2 December 2013 p1 WITN3499012

1445 Written Statement of David Cameron para 29 WITN3903007

1446 Written Statement of DavidCameron para 28 WITN3903007

1447 Memo from Ben Cole to PS(PH) and the Secretary of State 31 January 2014 p1 WITN3499013

1448 Memo from Ben Cole to PS(PH) and the Secretary of State 31 January 2014 p1 WITN3499013

By May 2014 ministers had agreed that there needed to be wholesale reform of the AHOs by rationalising them into one organisation, according to a chronology put together by the Department of Health.<sup>1449</sup> In February 2014 David Cameron was advised by his special adviser that “*Doing nothing is no longer an option*”;<sup>1450</sup> in June 2014 he was briefed that his special adviser was “*pushing DH*” to announce “*a review of the whole system of financial support for infected individuals and bereaved relatives*”,<sup>1451</sup> and in November 2014 was asked to approve a proposed consultation about the different schemes.<sup>1452</sup>

A view appears to have been taken that the necessary consultation on the shape of that reform would have to await the delivery of Lord Penrose’s report. It is not clear why this was, given that Lord Penrose was not considering the adequacy or otherwise of the financial assistance schemes. However, there may be some indication of the way the Prime Minister’s advisers thought: he received a submission on 24 November 2014 with the summary in bold: “*The big question, with the Penrose review in Scotland being delayed and delayed, and very little attention focusing on contaminated blood, is what the political upside would be of drawing attention to it now. There are some policy calls to make too.*”<sup>1453</sup> The submission proposed holding “*the package*” until Lord Penrose reported: saying “*Following [a constituency] meeting on 13th June, campaigners have recorded your commitment to ‘sort things out’ within 6 months ... But the decibel count is hardly high on the national register. There is little advantage to raising this issue pre-emptively in advance of Penrose reporting ... It raises an issue that is currently not generating negative coverage, and creates media moments (taking up grid slots) before the Election.*”<sup>1454</sup> This all suggests that presentation

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- 1449 Written Statement of Donna McInnes p15 WITN5737001. A submission to the Parliamentary Under-Secretary of State for Health, Jane Ellison, in May 2014 advised that there should be consultation with counterparts in Wales, Scotland and Northern Ireland to seek their views about scheme changes. Memo from Naomi Balabanoff to PS(PH) 30 May 2014 WITN3499014
- 1450 Memo from Nick Seddon and Maddy Phipps-Taylor to the Prime Minister 6 February 2014 p3 WITN3903009
- 1451 Memo from Nick Seddon to the Prime Minister 24 June 2014 p2 WITN3903010. He had met a constituent on 13 June 2014.
- 1452 Memo from Nick Seddon and Clare MacDonald to the Prime Minister 24 November 2014 p3 WITN3903012
- 1453 Memo from Nick Seddon and Clare MacDonald to the Prime Minister 24 November 2014 p2 WITN3903012. David Cameron noted in his statement “*I was increasingly frustrated at the delay in the publication of the Penrose report, not only for the sake of victims who had been waiting for so many years, but also because we were running out of time in the Parliament to respond with any meaningful reform.*” Written Statement of David Cameron para 43 WITN3903007. Jeremy Hunt would tell Parliament: “*It is with frustration and sincere regret that our considerations on the design of a future system have been subject to postponement whilst we awaited publication of Lord Penrose’s final report of his Inquiry in Scotland. We had hoped to consult during this Parliament on reforming the ex-gratia financial assistance schemes, considering, amongst other options, a system based on some form of individual assessment. However, I felt it was important to consider fully Lord Penrose’s report before any such consultation. Given its publication today, we clearly are not in a position to launch a consultation, on one of the last sitting days of this Parliament.*” Written Statement of Jeremy Hunt to the House of Commons 25 March 2015 p1 MACF0000022\_045. David Cameron added in his statement: “*It was regrettable that we had not been able to conduct a consultation into what a reformed system might look like*”. Written Statement of David Cameron para 50 WITN3903007
- 1454 Memo from Nick Seddon and Clare MacDonald to the Prime Minister 24 November 2014 p4 WITN3903012

trumped proceeding with policy – at least for the time being. David Cameron agreed to await the Penrose report.<sup>1455</sup>

The APPG on Haemophilia and Contaminated Blood was not held back by the imminent publication of the Penrose Report. It published its report in January 2015 entitled “*Inquiry into the current support for those affected by the contaminated blood scandal in the UK*”, accurately describing the current position as “*a haphazard financial support system, established piecemeal by successive governments*”.<sup>1456</sup> The findings made by the APPG included that there was a low level of awareness of the support available to those who were eligible (especially those infected with Hepatitis C) and that there was widespread dissatisfaction as to the way the support was delivered and the way in which the AHOs were funded. Importantly many respondents did not consider the available support was sufficient to meet their needs. The report made a number of recommendations including that:

- (a) the Department of Health should undertake a comprehensive review to consider measures to expand take-up of the support on offer.
- (b) the Department of Health should explore simplifying the five-trust structure.
- (c) a specialist service should be established to assist registrants to pursue lost medical records to assist in the registration process.
- (d) a public health doctor should carry out a comprehensive assessment of the needs of the beneficiaries and work out what it would cost to meet those needs. The appropriate level of funding for the organisations delivering assistance should be set at a level that was commensurate with beneficiaries’ needs.<sup>1457</sup>

## Reform of the Alliance House Organisations

On 25 March 2015 (the day of the publication of Lord Penrose’s report) David Cameron announced a consultation into reform of the AHOs. He pledged up to £25 million that financial year to support transitional arrangements to a better payments system as well as apologising for the infected blood scandal on behalf of the Government.<sup>1458</sup> That apology, however, was simply “*for something that should not have happened.*” It went no further.

The following day, on 26 March 2015 a statement was made to the Scottish Parliament by Shona Robison, the Cabinet Secretary for Health, Wellbeing and Sport who reaffirmed on

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1455 See the handwritten note. Memo from Nick Seddon and Clare MacDonald to the Prime Minister 24 November 2014 p2 WITN3903012

1456 The APPG on Haemophilia and Contaminated Blood *Inquiry into the current support for those affected by the contaminated blood scandal in the UK* p12 RLIT0000031

1457 The APPG on Haemophilia and Contaminated Blood *Inquiry into the current support for those affected by the contaminated blood scandal in the UK* pp95-97 RLIT0000031. There were 961 responses to the survey that informed the report.

1458 Hansard extract on Contaminated Blood 25 March 2015 p1 CELC0000002\_030, Written Statement of David Cameron paras 5-6 WITN3903001, Written Statement of David Cameron paras 45-50 WITN3903007, Written Statement of Jeremy Hunt to the House of Commons 25 March 2015 MACF0000022\_045

behalf of the Scottish Government the commitment to reviewing the existing schemes, by working with the other UK countries (as well as forming a patients and families reference group), with a view to concluding that work in time for an announcement no later than World Haemophilia Day in April 2016.<sup>1459</sup>

A meeting of the UK health departments took place on 17 April 2015 to discuss infected blood payments scheme reform. The minutes of the meeting record the desire of the English, Welsh and Northern Ireland Health Departments to work towards a UK-wide approach, and although it was noted that some “*affected patients*” in Scotland favoured a Scottish scheme in Scotland, Shona Robison was said to recognise that a UK-wide scheme would reduce service delivery costs.<sup>1460</sup>

On 30 June 2015 Jeremy Hunt wrote to David Cameron, suggesting that it was “*basically impossible*” to bridge the gap between the expectations of families who had suffered “*and what we can realistically afford.*” Time was said to be pressing due to litigation from Hepatitis C sufferers who were making the case that the current arrangements favoured HIV sufferers over those with Hepatitis C: “*Legal advice is that some are likely to succeed, and if the DH were ordered to recompense them, we would face a multi-million pound liability for compensation for them and others in similar circumstances.*” He put forward three options. The first was an “*austerity*” option which “*sticks to the £25m we promised before the election*”, using that sum to offer around £20k to all surviving bereaved spouses; the letter noted that “*Around 90% of bereaved families get nothing so they would benefit – but campaigners would be furious and consider it a slap in the face.*” The second option was to offer one-off payments both to existing sufferers and to bereaved families and to close down the payment schemes, with no further funding thereafter. It included accelerated access to treatment for all the 2,500 people thought to have been infected, rather than the 800 presently receiving it.<sup>1461</sup> This option (costed at £480m) was said to be currently unaffordable to the Department of Health and would require additional Treasury funding. The third option was to find an additional £100m from Department of Health funds which would be used to fund accelerated access to new Hepatitis C treatments for those in the early stage of the disease. He recognised that this option, which would involve no additional monies for any payment scheme, “*would not satisfy campaigners*”.<sup>1462</sup> The Prime Minister’s senior policy adviser recommended that he should proceed with Option 1. The Prime Minister said “*No.*” He also firmly rejected a proposal to withdraw support from uninfected family members, such as widows of those who had died following infection. His overall response was “*I don’t think these work. A scheme that is meant to help but actually takes money away from people who currently get it is hopeless. And I accept we don’t have £480m lying around. Surely there is*

1459 Hansard extract on Penrose Inquiry 26 March 2015 p3 WITN2287079. Her statement noted that the trusts for HIV predated devolution and were managed (ie funded) by the UK Department of Health.

1460 Minutes of UK Health Departments Infected Blood Payments Scheme Reform meeting 17 April 2015 pp1-2 WITN4688017

1461 This would have to be funded by paying for private treatment, because NHS funds could not be used “*to allow them to jump the queue ahead of other NHS patients in greater clinical need.*” Letter from Jeremy Hunt to David Cameron 30 June 2015 p3 CABO0000163\_003

1462 Letter from Jeremy Hunt to David Cameron 30 June 2015 p3 CABO0000163\_003

*a route where we increase the £25m to £100m or some such and fill in the worst payment gaps & merge all the charities into 1.*<sup>1463</sup>

Following further deliberations,<sup>1464</sup> a submission to Jane Ellison and Jeremy Hunt in early August 2015 identified three different options, in the context of “*two steers: to make as few changes as possible, and for no losers compared to the current scheme.*” Option one was to reform the current schemes into one non-charitable scheme with no additional spend. It was noted that “*The reputational risk of failing to make substantive changes to the scheme is high. Successive Governments have promised to address the concerns of beneficiaries for a number of years.*” Option two was to reform the current schemes into one, using the £25m already agreed to provide £5m additional funding a year for the next five years, and option three was as per option two but with £25m additional funding a year for the next five years.<sup>1465</sup>

In November 2015 the Spending Review resulted in an increase in the overall funding for the NHS and agreement that a further £25m per year would be allocated from Department of Health central funds to the financial support schemes over the following five years.<sup>1466</sup>

## **Scotland: establishment of Scottish Infected Blood Support Scheme (“SIBSS”)**

A report was published in March 2015 as a result of the survey that had been commissioned by the Scottish Government Health and Social Care Directorate in 2014 on the support needs of those infected by Hepatitis C. The report, entitled “*Hepatitis C Virus (HCV) Contaminated Blood Scoping Exercise*”, aimed to assist the Scottish Government in understanding more clearly the scope and scale of the unmet needs resulting from Hepatitis C infection and to detail the support required by those affected.<sup>1467</sup> It made a number of recommendations including that:

- (a) financial recompense for elevated living costs that were attributable to Hepatitis C infection from contaminated blood, as well as loss of potential earnings over the life course, should be addressed.
- (b) the outstanding recommendations made by Lord Ross’s expert group on financial support<sup>1468</sup> should be implemented.

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1463 Emphasis in original. Memo from Clare MacDonald to the Prime Minister 5 July 2015 CABO0000163\_002

1464 Written Statement of Jeremy Hunt paras 33.36-33.41 WITN3499001

1465 Memo from Naomi Balabanoff to PS/PS(PH) and PS/SoS WITN3499024

1466 Written Statement of Jeremy Hunt para 33.42 WITN3499001. It appears that the health departments in Northern Ireland, Scotland and Wales were not given prior warning either about the £25m announced by the Prime Minister in March 2015, or about the further £100m which was announced as part of the consultation issued in January 2016. Memo from Karen Simpson to Simon Hamilton 22 January 2016 p2 DHNI0001449

1467 Scottish Infected Blood Forum *HCV Contaminated Blood Scoping Exercise: Final Report* March 2015 p7 WITN7165010

1468 Report of the Expert Group on Financial and Other Support March 2003 HSOC0020367



- (c) insurance/assurance products and services should be made available to people infected by Hepatitis C through contaminated blood at levels commensurate with the general public.
- (d) Professional counselling services should be made available.<sup>1469</sup>

By June 2015 (some two months after the publication of the Penrose Report), the Scottish Government established a Financial Review Group to provide recommendations to Scottish Ministers on whether the current financial support schemes should be changed and if so what changes should be made and whether any of them should be retrospective. Importantly the Group included people infected and their family members together with Scottish Government officials and other interested parties.<sup>1470</sup>

In its final report published in December 2015, the Financial Review Group made a number of recommendations both about the level at which payments should be made, and to whom, including that the annual payments should be increased to reflect the Scottish full-time gross median income and that bereaved partners should receive a corresponding pension of 100% of the annual payment in the first year and 75% thereafter.<sup>1471</sup> The Group “favoured a new Scottish scheme that would not be constrained by UK-wide discussions/agreement”<sup>1472</sup> which had been one of the difficulties the Scottish Government faced when seeking changes in levels of assistance from the AHOs, as any change required all four nations to agree and to identify additional funding.<sup>1473</sup>

The proposals made by the Financial Review Group were accepted by Shona Robison, Cabinet Secretary for Health, Wellbeing and Sport, in March 2016,<sup>1474</sup> confirming that “a new Scottish scheme will be established for people who became infected with HIV and hepatitis C after treatment in Scotland, and their dependents”,<sup>1475</sup> with the result that the SIBSS was

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1469 Scottish Infected Blood Forum *HCV Contaminated Blood Scoping Exercise: Final Report* March 2015 pp104-109 WITN7165010

1470 The Group Membership and Terms of Reference are at Annexes A and B. Financial Review Group *Contaminated Blood: Financial Support: Conclusions and Recommendations* 2015 pp38-39 WITN4508014

1471 Other recommendations included that those with a chronic Hepatitis C infection should receive a payment of £50,000 at stage 1 Hepatitis C and £20,000 at stage 2 together with greater funding for a discretionary grant scheme with minimised assessment with other aspects to be subject to continuing review. Financial Review Group *Contaminated Blood: Financial Support: Conclusions and Recommendations* 2015 pp3-4 WITN4508014

1472 Financial Review Group *Contaminated Blood: Financial Support: Conclusions and Recommendations* 2015 p9 WITN4508014

1473 Samantha Baker Transcript 18 May 2021 pp16-17 INQY1000118. Samantha Baker was not at the time the policy lead for blood, as she later became in the Scottish Government.

1474 Written Statement of Shona Robison paras 19-20 WITN6648002, Written Statement of Mairi Gougeon para 3.3 WITN5672001

1475 Scottish Government News *Extra £20 million for infected blood support* 18 March 2016 MACF0000027\_028

established, to be administered by the Common Services Agency for the Scottish Health Service,<sup>1476</sup> and began operations on 1 April 2017.<sup>1477</sup>

In common, however, with the AHOs, the new scheme expressly remained one for the making of ex gratia payments.<sup>1478</sup> They were not intended to be compensatory.<sup>1479</sup> The same is true for the other three national schemes, discussed below.<sup>1480</sup>

In mid-2017, however, a further review was undertaken in Scotland. Since this considered the English approach to a third level of support – one sitting between stage 1 and stage 2 as they had been under the Skipton Fund – before determining on an approach it considered better, the English approach needs first to be explained. It sits within the context of the England Infected Blood Support Scheme.

## England: establishment of England Infected Blood Support Scheme (“EIBSS”)

Although Jeremy Hunt’s statement of 25 March 2015 had expressed frustration and regret that decision making had been subject to postponement whilst awaiting publication of the Penrose report (“*We had hoped to consult during this Parliament on reforming the ex-gratia financial assistance schemes, considering, amongst other options, a system based on some form of individual assessment*”)<sup>1481</sup> it took until 21 January 2016 – ten months after the report was published – for the Department of Health to launch a consultation on the reform of the AHOs in England. The consultation document set out a number of proposals for a new scheme in England, and included a commitment of a further £100m of funding (additional to the £25 million committed by David Cameron in March 2015).<sup>1482</sup> It avoided an unpublished suggestion by the Department of Health that “stage 2” awards in the Skipton fund should

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1476 Commonly known as National Services Scotland.

1477 While SIBSS was being set up, the Scottish Government made the payments at the new level through the Skipton Fund and MFET Ltd. from December 2016. Samantha Baker Transcript 18 May 2021 p9, p26 INQY1000118

1478 See the first recital to the memorandum of agreement between the Scottish Ministers and National Services Scotland. Memorandum of Agreement in respect of the operation of the Scottish Infected Blood Support scheme 9 March 2017 p2 WITN4728006

1479 Mairi Gougeon and Samantha Baker Transcript 18 May 2021 pp36-37 INQY1000118

1480 See, in relation to Northern Ireland, the evidence of Robin Swann Transcript 19 May 2021 pp41-43 INQY1000119, in relation to Wales Written Statement of Vaughan Gething on Future Support for those Affected by Contaminated Blood Following NHS Treatment 30 March 2017 CVHB0000040, and in relation to England the evidence of Matt Hancock: “*it is not a compensation scheme. It is a support scheme.*” Matt Hancock Transcript 21 May 2021 p126, pp150-151 INQY1000121

1481 Written statement of Jeremy Hunt to the House of Commons 25 March 2015 p1 MACF0000022\_045

1482 Department of Health *Infected Blood: Reform of Financial and Other Support* January 2016 p5 WITN3904006. The consultation was open until 15 April 2016. It was issued by the Department of Health (page 3), and the additional funding was to be for England (page 5), but the consultation was described as “*led*” by the Department of Health (which might suggest that others had a role albeit a minor one and that it was open to anyone in the UK to respond (page 5). Page 13 says the proposals under consultation were to replace the five schemes “*with one operated by a single body*” (which would suggest one UK national scheme), yet also to those infected in England. Page 37 however refers to the UK Health Departments. A reader might not realise from this consultation paper that it was proposed to set up four national schemes, rather than one for the UK as a whole (though the latter would require the agreement of the devolved administrations).

be dispensed with, on the basis that these awards might incentivise people not to accept treatment, but allow their condition to worsen so that they received the money instead. To his credit, David Cameron responded by describing this view as “*wrong*” and that making that proposal was “*CRASS*” and “*Deeply condescending*”. He added “*Slightly losing confidence in DH. And they have a dreadful reputation with sufferers on this. We want MORE where possible and not balanced by LESS for anyone. Come and explain if necessary.*”<sup>1483</sup>

Little notice of the consultation was given to the health ministers in Scotland, Wales and Northern Ireland.<sup>1484</sup>

On 13 July 2016, nearly 16 months after the Penrose Inquiry report had been published, the Department of Health published its response to the consultation, setting out its decision to have a single scheme administrator that would become operational in 2017/2018. It also announced the lump sum, annual and discretionary payments that would be made by the new scheme.<sup>1485</sup> The resulting proposals were applicable to England only, and announced by David Cameron on that day.<sup>1486</sup>

On 6 March 2017 the Department of Health announced that the NHS Business Services Authority would administer the scheme.<sup>1487</sup>

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1483 Emphasis in original. Memo from Clare MacDonald to the Prime Minister 13 January 2016 CABO0000165\_002.

1484 Shona Robison told the Inquiry that Jane Ellison called her just before the consultation was launched to brief her on its contents; her understanding was that Scottish Government officials were not shown the consultation paper until the day it was published. Written Statement of Shona Robison para 59 WITN6648002. An internal Department of Health, Social Services and Public Safety for Northern Ireland submission records that “*The other 3 UK Health Departments were given no prior notice about the date of issue, other than that it would likely be in January, and were only informed last week that they would not have an opportunity to see the document before it was issued.*” Memo from Karen Simpson to Simon Hamilton 22 January 2016 p1 DHNI0001449. This does not reflect what Parliament had been told on 20 July 2015, namely that “*The four UK Health Departments have been working together closely on this matter and will continue to do so. As a result of the direct links established between the Scottish Government and patient groups in Scotland following the publication of the Penrose Inquiry, the Scottish Government are undertaking their own consultation with patient groups in Scotland. We look forward to seeing the results of that activity. When we launch our consultation later this year, we will continue to work with Scotland. That will enable all four countries to share their learning and therefore have far more robust information to inform the shape of any future reformed scheme.*” Hansard extract on Contaminated Blood 20 July 2015 RLIT0001576

1485 Department of Health *Infected Blood: Government Response to Consultation on Reform of Financial and Other Support* July 2016 pp17-18 WITN3953052. New stage 1 Hepatitis C entrants to the scheme were to continue to receive a one-off lump sum payment of £20,000 as well as being eligible to receive a new annual payment of £3,500, rising to £4,500 in 2018/19. Those who progressed to stage two remained entitled to a £50,000 lump sum payment. Annual payments for those with stage 2 Hepatitis C, HIV or co-infection were uplifted and a new one off £10,000 payment introduced for bereaved partners and spouses. The response also set out that a new special appeals mechanism would be implemented for those at Hepatitis C stage 1 who considered the impact of their infection to be such that they should qualify for stage 2 annual payments, without the need for an individual health assessment.

1486 House of Commons debate 13 July 2016 RLIT0002408, Written Statement of David Cameron para 58 WITN3903007

1487 Hansard written statement on Health Redress 6 March 2017 RLIT0002353

The Department of Health issued a further consultation on 6 March 2017 relating to a proposed special category mechanism (“SCM”).<sup>1488</sup> Six months later the Department of Health published its response announcing a new mechanism to enable a beneficiary with a stage 1 infection which was having a substantial and long-term negative impact on their daily lives, to apply for a higher annual payment. Each application had to be supported by medical evidence. Annual support payments were also to be uplifted and discretionary support harmonised under the single administrator.<sup>1489</sup>

On 1 November 2017, the EIBSS became operational.<sup>1490</sup>

## Establishment of the Infected Blood Payment Scheme for Northern Ireland

Advance notice of the Department of Health’s consultation was not provided to Northern Ireland. Lines to take drafted for the Minister of Health Simon Hamilton following the publication of the consultation in January 2016 expressed disappointment *“that my department was not given the opportunity to see the consultation document before publication so that any concerns could be addressed”* and stated that the outcome of the consultation would be awaited before any decision was taken.<sup>1491</sup>

Advance notice of the Department of Health’s response to the consultation was also not provided to Northern Ireland.<sup>1492</sup> A submission to Michelle O’Neill, the new Minister of Health, in July 2016 explained that the Department of Health (London) had informed the devolved administrations that no additional money would be available for them. The submission added:

*“From 2014 it was agreed at Ministerial level that officials in England, Scotland, Wales and north of Ireland should work together to establish a consistent model of financial assistance across the UK with the aim of rationalising the current five financial assistance schemes for health service patients affected by infected blood under one single legal entity. However there have been difficulties with this working relationship, in particular with officials in the DAs being unsighted on a number of important announcements made by England on the issue. This includes the announcement of the consultation on scheme reform and now the*

1488 Department of Health *Infected Blood: Consultation on Special Category Mechanism and Financial and Other Support in England* 6 March 2017 pp5-6 WITN4688037. The SCM was for beneficiaries with Hepatitis C stage 1 who considered their infection or treatment had a substantial and long-term adverse impact on their ability to carry out routine daily activities, but who did not meet the criteria for stage 2 payments.

1489 Department of Health *Infected Blood: Government Response to Consultation on Special Category Mechanism and Other Support in England* 28 September 2017 DHSC0050134. The application form is at Annex A.

1490 Written Statement of Brendan Brown para 15 WITN4496001

1491 Memo from Karen Simpson to Simon Hamilton 22 January 2016 p6 DHNI0001449

1492 Letter from Jane Ellison to Michelle O’Neill WITN4066012, Memo from Karen Simpson to Michelle O’Neill 22 July 2016 p2 WITN4066020

*government response, despite repeated requests from officials in Scotland, Wales and the north of Ireland for the information to be shared.”*<sup>1493</sup>

The submission identified four options for the Minister of Health – to maintain the status quo and retain the pre-reform payment levels, to replicate the Scottish reform (described as “*more costly to replicate ... than the English plans*”, to increase and reform payments in line with England, or to design a bespoke scheme for Northern Ireland.<sup>1494</sup> The recommendation from officials was to continue the “*current forms and levels of assistance, on grounds of affordability*”.<sup>1495</sup> As at October 2016 the Minister was still considering the options and was pressed by officials on 17 October for an urgent decision to be taken “*on whether enhanced payments will apply in the north of Ireland or whether the status quo should continue (previous recommended option)*.”<sup>1496</sup>

After almost six months, the Minister decided that the new provisions being introduced in England should be replicated in Northern Ireland, though with no commitment to introduce a special category mechanism.<sup>1497</sup> She announced this by way of statement to the Assembly on 22 December 2016.<sup>1498</sup>

On 16 January 2017, the Northern Ireland Executive collapsed leaving the Department of Health without a minister for the following three years and limiting its ability to implement reforms.<sup>1499</sup>

When the Department of Health in England directed the NHS Business Services Authority to administer payments in March 2017, Lord O’Shaughnessy, the Parliamentary Under-Secretary of State for Health, wrote to the Head of the Northern Ireland Civil Service stating that the remit of the NHS Business Services Authority did not cover Northern Ireland, therefore it would not be able to offer scheme administrative services to Northern Ireland beneficiaries. The Health Protection Branch executives quickly submitted a Strategic Outline Business Case to the Director of Finance on 21 March 2017 suggesting the Business Services Organisation<sup>1500</sup> take the same role in Northern Ireland. It was noted that the additional funding for the scheme was an “*inescapable pressure*” and that administrative costs would be higher as there would be no shared services with the other UK health administrations.<sup>1501</sup>

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1493 Memo from Karen Simpson to Michelle O’Neill 22 July 2016 pp4-5 WITN4066020

1494 Memo from Karen Simpson to Michelle O’Neill 22 July 2016 pp7-9 WITN4066020

1495 Memo from Karen Simpson to Gerard Collins and Michelle O’Neill 12 September 2016 p2 WITN4066021, Memo from Karen Simpson to Michelle O’Neill 22 July 2016 p10 WITN4066020

1496 Memo from Karen Simpson to Gerard Collins and Michelle O’Neill 17 October 2016 p4 WITN4066022

1497 Written Statement of Michelle O’Neill para 3 WITN7069001

1498 Written Statement of Michelle O’Neill to the Northern Ireland Assembly 22 December 2016 p1 WITN4066006

1499 Written Statement of Elizabeth Redmond para 5.2 WITN4066002

1500 Northern Ireland’s business services body and its equivalent to the NHS Business Services Authority.

1501 Memo from Liz Redmond to Neelia Lloyd 21 March 2017 p4 WITN4066007

Letters were issued on 11 October 2017 to beneficiaries advising them that the scheme would become operational on 1 November 2017 with continuity of payments.<sup>1502</sup>

## Establishment of the Welsh Infected Blood Support Scheme (“WIBSS”)

Wales, like Northern Ireland, did not receive advance notice of the consultation or of the Department of Health’s response, and was left with little choice but to set up a Welsh scheme in consequence of the decisions and actions being taken to set up an English scheme and a Scottish scheme.<sup>1503</sup>

On 6 October 2016 Vaughan Gething, as Cabinet Secretary for Health, Well-being and Sport for Wales, made an announcement aimed at ending uncertainty about the level of support available from the Welsh Government. Noting that the UK wide nature of the schemes had “*now fragmented through new schemes announced for Scotland and England*”, he stated that as an interim measure payments for the remainder of the 2016-17 financial year would be at the same levels as England. He announced a consultation on the terms of the scheme from April 2017 onwards.<sup>1504</sup> He wrote to the 280 people in Wales who were being supported through the AHOs asking for their views on support in the future, and two workshops were held at which people could contribute their views.<sup>1505</sup>

The results of that consultation led to Vaughan Gething making a written statement on 30 March 2017 setting out the new arrangements for a Welsh scheme. This was to be administered by Velindre NHS Trust through the NHS Wales Shared Services Partnership. All beneficiaries would automatically transfer to the new scheme operational from October 2017. A new feature was payments to bereaved spouses and partners of 75% of the regular payments for three years after bereavement. Finally, the Welsh scheme offered a holistic advice service from implementation relating to healthcare services, home or travel insurance, other financial benefits or other public services.<sup>1506</sup>

## Scottish approach to an intermediate category of payment

In mid-2017 the Scottish Government asked Professor David Goldberg (Health Protection, Scotland) to establish and preside over an expert group to assess the health and wellbeing of individuals, chronically infected with the Hepatitis C virus (those at stage 1) who had not yet progressed to advanced Hepatitis C (those who had been eligible for Skipton Fund “stage Two”). The expert group recommended that a further (kidney) condition should be

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1502 Letter from Business Services Organisation on Northern Ireland Infected Blood Support Scheme 11 October 2017 DHNI0001143

1503 Vaughan Gething Transcript 20 May 2021 p9 INQY1000120

1504 Written Statement of Vaughan Gething on Wales reform of financial support for those affected by NHS supplied contaminated blood 6 October 2016 WIBS0000054

1505 Written Statement of Vaughan Gething para 5 WITN5665001

1506 Welsh Government Survey: Summary of responses 30 March 2017 WITN5665002, Written Statement of Vaughan Gething on Future Support for those Affected by Contaminated Blood Following NHS Treatment 30 Mar 2017 CVHB0000040

added to the advanced Hepatitis C criteria, because it was a consequence of Hepatitis C infection which had a substantial negative impact on life expectancy.<sup>1507</sup> More significantly for many, it considered whether a *“method, permitting the robust and rigorous assessment of the impact of hepatitis C on the individual who has not progressed to advanced liver disease, could be developed and command the confidence of both assessors (clinical staff) and assessees (patients).”*<sup>1508</sup>

It then examined the English model. To qualify in England, an individual had to answer two questions:

- *“Does your hepatitis C infection or its treatment make it difficult for you to carry out regular daily activities such as leaving your home, using public transport or shopping for essentials, as a result of mental health problems (such as feeling depressed or feeling anxious)?*

*Yes/No and if Yes, occasionally/monthly/weekly/most days/daily*

- *Does your hepatitis C infection or its treatment make it difficult for you to carry out regular daily activities such as walking more than 50 meters [sic], climbing stairs, lifting objects from the ground or a work surface in the kitchen, or physical tasks such as gardening?*

*Yes/No and if Yes, occasionally/monthly/weekly/most days/daily”.*

The attending hospital doctor or viral hepatitis nurse had to respond in the following way:

- *“Confirm that the patient is suffering from mental health problems and/or fatigue and provide detail about the nature of the problems.*
- *Answer the following question. In your opinion how likely is it that your patient’s a) mental health problems and/or b) fatigue are attributable to their hepatitis C infection (or its treatment effects)?”*<sup>1509</sup>

There was a general agreement in Scotland – involving a wider group than the Review Group itself, including clinical leads and/or Hepatitis C coordinators from Scotland’s NHS boards and Professor Goldberg’s Clinical Review group – that the English model should not be followed because it *“i) did not take account of the past impacts of hepatitis C on the current and future lives of infected people and their widows/widowers/civil partners, ii) would likely have a deleterious effect on the doctor-patient relationship and iii) was not robust enough to allow assessment with any precision.”*<sup>1510</sup>

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1507 It was renal disease due to membranoproliferative glomerulonephritis (MPGN): see Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 p7 GGCL0000168

1508 Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 p41 GGCL0000168

1509 Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 pp41-42 GGCL0000168

1510 Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 p42 GGCL0000168

Having examined a range of alternative approaches, involving the establishment of thresholds of one kind or another, the group observed that *“The complexity of the impacts of hepatitis C on the individual, particularly from a psychosocial perspective, was viewed as so considerable that it would be inappropriate to undertake any such individual assessment, no matter how sustained and rigorous it might be, on the grounds that the end result would often be an unfair one, subject to contestability.”* It noted that any assessment which was just clinically-based would ignore the very considerable non-clinical impacts as described in its report.<sup>1511</sup>

On that basis, it unanimously favoured people with chronic Hepatitis C, including those who had cleared their virus through treatment, or their widows, widowers or partners who were eligible for support being asked to *“self-declare hepatitis C impact in the following simple way.*

- *If they themselves considered that their (or their spouse’s/partner’s) hepatitis C had not appreciably affected their life, they would not be eligible for a chronic HCV annual payment award; however if the situation changed in the future and they considered that hepatitis C was now affecting their life, they could apply for a chronic HCV award as below.*
- *If they themselves considered that their (or their spouse’s/partner’s) hepatitis C had seriously affected and continued to affect their life, they would be eligible for a chronic HCV award at a higher level.*
- *If they themselves considered that their (or their spouse’s/partner’s) hepatitis C had affected and continued to affect their life, but not seriously, they would be eligible for a chronic HCV award at a lower level.”<sup>1512</sup>*

This was entirely based on trusting the judgement of the potential applicant, and there was no need for a healthcare professional to be involved. It was thought optimal because it would be:

*“simple to administer, it aims to ensure that those with the greatest need receive the greatest benefit, it avoids patient/healthcare professional conflict and any need for an appeals process, it reduces stress among applicants to a minimum, it is person-centred recognising that the individual’s perception of hepatitis C is critical, it promotes both individual and collective responsibility and it sends out a loud and clear message saying ‘you are trusted to make the appropriate declaration’.”<sup>1513</sup>*

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1511 Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 pp42-43 GGCL0000168

1512 A definition of “serious” would be provided to assist decision-making, but there would be no requirement to justify the application or the category they declared themselves in: Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 pp43-44 GGCL0000168

1513 Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 p44 GGCL0000168



This was a bold, innovative approach to take. It is likely to have owed much to the presence of people with Hepatitis C infection amongst the members of the Review Group. It was adopted. Though it is challenging to assess whether all the assessments are fair, when the only way of judging that is to accept the judgement of the person making it, the feedback to this Inquiry has been that it seems to work well, as predicted, though some people found the self-assessment daunting. There has been no claim that the system has encouraged any overpayment.<sup>1514</sup>

Bill Wright, the chair of Haemophilia Scotland, which was heavily involved in the establishment of SIBSS, a significant campaigner, and a member of the Review Group summed it up:

*“We ... focused on the lack of trust felt by survivors under existing schemes and a rather novel solution was proposed. On the basis that the mental health impacts were ‘incontrovertible’, provision should be made for those under the scheme as ‘Stage one’ recipients to self-assess as minimally affected, moderately affected or severely affected. We felt that this might restore a sense that the mental stresses were being recognised by those in authority.”*<sup>1515</sup>

On the financial and clinical review groups he said: *“I felt that the voices of the infected and affected had, for once, been listened to.”*<sup>1516</sup>

## Changes since the start of the national support schemes

Changes have been made to all four schemes since their inception, often following dogged campaigning by those infected and affected. Among the more significant changes are:

- (a) **SIBSS**: the introduction of self-declaration in Scotland, following Professor Goldberg’s review. This change was implemented in December 2018.<sup>1517</sup>
- (b) **WIBSS** introduced a version of the special category mechanism in April 2019, called the Enhanced Hepatitis stage 1+ payment. This was for WIBSS beneficiaries

1514 Martin Bell, the director in NHS National Services Scotland with responsibility for the Scotland Infected Blood Support Scheme, was asked if there are any drawbacks to the self-certification process. His response was: *“From our perspective, working on the assumption that we trust our members, then we don’t see why we would introduce additional bureaucracy which could potentially slow things down -- we don’t think that would work.”* Martin Bell Transcript 18 May 2021 p163 INQY1000118

1515 Written Statement of Bill Wright paras 20.33-20.34 WITN2287019. Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 p12, p9 GGCL0000168

1516 Written Statement of Bill Wright para 20.42 WITN2287019. Samantha Baker said that the Scottish Government and SIBSS had made a number of other changes as a result of stakeholder or beneficiary feedback including: extending payments for bereaved partners to long-term cohabiting partners; introducing annual payments for those with chronic Hepatitis C and their bereaved partners; lump sum payments of £30,000 for bereaved partners of people with chronic Hepatitis C who had died and not received this additional sum; applying Consumer Price Index increases to annual payments from April 2020 onwards; and ensuring that grants for counselling support were easier to access without any means testing. Written Statement of Samantha Baker p6, pp10-11 WITN0713015

1517 Written Statement of Mairi Gougeon para 3.10 WITN5672001. This can be contrasted with the position in England, where EIBSS beneficiaries had to be subjected to professional assessment in order to qualify for the SCM payments.

with chronic Hepatitis C infection, at stage 1, who were experiencing significant mental health issues or post-traumatic stress related to their infection which were affecting their ability to carry out day-to-day activities. It included beneficiaries who had HIV and Hepatitis C stage 1 infections. Applicants were able to self-certify,<sup>1518</sup> and received the same annual payment as those who were eligible for the stage 2 payment.<sup>1519</sup>

- (c) **EIBSS:** on 30 April 2019 the Prime Minister announced that £30 million of additional funding would be made available.<sup>1520</sup> This announcement coincided with the first day on which the Inquiry heard evidence. The timing of the announcement was not coincidental – this is not to say that the money would not necessarily have been found in due course, but it is more that the likely publicity of the start of the Inquiry hearings was what focused the departmental/governmental mind.<sup>1521</sup> While not all the contemporaneous reporting made it clear, this was an announcement that applied only in England. The changes meant that from July 2019 EIBSS introduced increased and consolidated payments for all infected beneficiaries, removing the need for beneficiaries to apply separately for income top-up payments.<sup>1522</sup> The minister responsible, Jackie Doyle-Price, reflected “*I was able to achieve an uplift in payments to achieve parity with Scotland, but it is fair to say that that caused issues for Wales and Northern Ireland.*”<sup>1523</sup>

Officials in Northern Ireland described the decision to raise payments as “*a political decision*”, not underpinned by a defensible rationale, “*so there is no DHSC [Department of*

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1518 Vaughan Gething described the reasons for opting for this model, rather than one requiring clinical evidence, in his oral evidence: “*it’s an understanding of the hurt that people have already gone through*”. Vaughan Gething Transcript 20 May 2021 pp28-29 INQY1000120

1519 Written Statement by the Welsh Government March 2019 WITN4065002

1520 Gov.uk *Infected blood scandal: increased financial support for victims confirmed* 30 April 2019 RLIT0002051

1521 In response to the question “*Is it right that the Department was very keen in terms of the timing of this announcement for the announcement to be made because the Infected Blood Inquiry was about to start hearing evidence from victims?*” William Vineall said “*Yes*”, whilst adding that “*It’s also true that we wanted to make the change and make it happen -- I mean, regardless of the Inquiry, if you know what I mean.*” William Vineall Transcript 21 May 2021 p118 INQY1000121. Another document reported that “*Cabinet Office was keen for any announcements [to] be made prior to the Infected Blood Inquiry resuming their gathering of evidence from 30 April 2019.*” Infected Blood: Parity of Support across UK p1 HSSG0020025. This had been the deadline given by campaigners when they met David Lidington (Chancellor of the Duchy of Lancaster and Minister for the Cabinet Office) and Jackie Doyle-Price (Parliamentary Under-Secretary of State in the Department of Health and Social Care) in January 2019 following my letter to David Lidington after the Inquiry’s preliminary hearings – but campaigners sought parity across the UK. Email from Tim Jones to Ailsa Wight, Ginny Belson and Emily Coelho 21 January 2019 DHSC0050584, Letter from Sir Brian Langstaff to David Lidington 15 October 2018 DHSC0050495. William Vineall said that cross-UK parity was “*parked because we wanted to take the action.*” William Vineall Transcript 21 May 2021 pp121-122 INQY1000121, Infected Blood: Parity of Support across UK p1 HSSG0020025. There was a similar coincidence of timing two years later just before the then Secretary of State, Matt Hancock, and the health ministers from Scotland, Northern Ireland and Wales were due to give evidence.

1522 Written Statement of William Vineall para 21 WITN4688055

1523 Written Statement of Jackie Doyle-Price para 21 WITN6650001

Health and Social Care] *analysis from which we could extrapolate.*<sup>1524</sup> Vaughan Gething referred to the money being found “*essentially down the back of the departmental sofa*”; there was no consequential provision beyond England because the money came from within the Department of Health and Social Care’s existing budget and was not a new allocation from the Treasury.<sup>1525</sup>

At the centre of this announcement was concern which had been expressed about different levels of payment in the four nations. This unilateral move on the part of England to increase payments (the devolved schemes did not even receive advance notification of the uplift)<sup>1526</sup> intensified calls for parity between the schemes.

### Parity of provision

It had been clear from the outset that there was no parity of provision between England and Scotland. This is despite it having been an aim of the reforms that “*the systems in England could harmonise with those in Scotland*” according to the then Prime Minister David Cameron.<sup>1527</sup> Nor was there parity of provision with Wales and Northern Ireland.

Jane Ellison told the Inquiry that it was “*clearly desirable to strive for parity between the administrations, mainly because it was fairer to the beneficiaries. However ... the department in England could not impose the principle of parity.*”<sup>1528</sup> Jeremy Hunt suggested that:

*“Whilst parity between the devolved schemes would have been desirable, Health functions were devolved and each Administration had constitutional responsibility for its own scheme. Responsibility for the infected blood payment schemes was therefore a matter for each devolved administration, each administration was financially responsible for beneficiaries in its jurisdiction, and parity across the schemes could not be imposed.”*<sup>1529</sup>

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1524 Submission from Seamus Camplisson to Richard Pengelly and Robin Swann 4 March 2020 p18 WITN5570021

1525 Vaughan Gething Transcript 20 May 2021 pp100-101 INQY1000120, Written answer on Blood: Contamination 12 June 2019 RLIT0001496, Submission from Seamus Camplisson to Richard Pengelly and Robin Swann p5 WITN5570021

1526 William Vineall explained that this was because the agreement and the money was dependent on a number of other agreements that were part of a package, but unrelated to infected blood. William Vineall Transcript 21 May 2021 p116 INQY1000121. Vaughan Gething explained the frustrations and difficulties that this caused in Wales: “*the increase was essentially the first day of the Inquiry sitting and we certainly didn’t have notice of that. The frustration was that there had been a meeting between officials between governments I think in the week before, and there wasn’t any sharing or conversation about that*”. Vaughan Gething Transcript 20 May 2021 pp38-39 INQY1000120. He told the Inquiry that there had never been an explanation as to why no advance notice was given: Vaughan Gething Transcript 20 May 2021 p65 INQY1000120

1527 Written Statement of David Cameron para 32 WITN3903007. He added “*(after all, the problem with past systems was too much fragmentation)*.” Harmonising “*systems*” may not be the same as “*harmonising payments*”, though this depends on how the word “*systems*” is to be understood.

1528 Written Statement of Jane Ellison para 51 WITN3904009. Her recollection was that “*Scotland preferred to make different choices on scheme reform and not be bound to England’s direction of travel*”.

1529 Written Statement of Jeremy Hunt para 40.4 WITN3499001

Jackie Doyle-Price acknowledged that parity between the four schemes “*was an important objective, because looking at the financial schemes from the perspective of an individual beneficiary, there is a clear issue of fairness.*”<sup>1530</sup>

Jackie Doyle-Price was not aware if any steps were taken by the Department of Health to achieve parity when the devolved schemes were being set up.<sup>1531</sup> Samantha Baker (the team leader with overall responsibility for infected blood within the Scottish Government’s Health Protection Division) told the Inquiry that parity had not been a prominent part of the regular four nations’ meetings until 2019.<sup>1532</sup> William Vineall likewise was not aware of measures being put in place at the outset to try and minimise the extent of disparity.<sup>1533</sup>

After the uplifts in England, a group of campaigners wrote to Prime Minister Theresa May on 8 May 2019 requesting that similar payment uplifts be made across all of the devolved nations.<sup>1534</sup>

On 10 July 2019, a telephone conference took place between the four nations’ Ministers,<sup>1535</sup> where the problem of disparity of support was discussed for the first time. Neither Wales nor Northern Ireland had funding available within their existing health budgets to make equivalent uplifts to that made by EIBSS. In Wales the disparity had led to the expression of “*strong views from their infected and affected campaigners*” and in Northern Ireland it had caused “*considerable distress*” among beneficiaries and campaigners. There was however a commitment made to achieving parity of support and an agreement that each nation should give one another due warning of any intended changes to support provided.<sup>1536</sup>

On 23 July 2019 David Lidington, Chancellor of the Duchy of Lancaster and Minister for the Cabinet Office, sent a letter to Jackie Doyle-Price copied to the Chief Secretary to the Treasury asking the Treasury to give urgent consideration to agreeing the disbursement of funds to Northern Ireland and Wales in order to correct the disparity caused by the uplifts made in England. The disparity caused by the announcement on 30 April 2019 “*was inadvertent but I believe now needs to be corrected urgently.*”<sup>1537</sup>

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1530 Written Statement of Jackie Doyle-Price para 18 WITN6650001

1531 Written Statement of Jackie Doyle-Price para 20 WITN6650001

1532 Samantha Baker Transcript 18 May 2021 p66 INQY1000118

1533 William Vineall Transcript 21 May 2021 p156 INQY1000121. He added that “*normal devolution practice is you establish things and the point of the devolution is to allow those devolved administrations to make decisions.*”

1534 Letter from campaigners and charities to Theresa May 8 May 2019 DHSC0050700

1535 In the case of Northern Ireland there was at that stage no minister, and Northern Ireland was represented by officials (Richard Pengelly, Sue Gray and Lesley Heaney).

1536 Four Nation Ministerial teleconference: parity of support between infected blood support schemes 10 July 2019 WITN5665003

1537 Letter from David Lidington to Jackie Doyle-Price 23 July 2019 p1 DHSC0050708. It was his penultimate day in office. The next day there was a new Prime Minister and the Chief Secretary to the Treasury changed from Liz Truss to Rishi Sunak, with Sajid Javid becoming Chancellor of the Exchequer.

In October 2019 Welsh ministers wrote to the Department of Health, urging the provision of funding necessary to enable the Welsh Government to work towards parity of support.<sup>1538</sup>

On 9 January 2020, three years after the collapse of the Northern Ireland Assembly, a deal to restore devolved government in Northern Ireland, *New Decade, New Approach*, was agreed by all the Northern Irish political parties. This agreement included the intention of the Executive to bring about parity in financial support in Northern Ireland with that in England.<sup>1539</sup> The newly appointed Health Minister, Robin Swann, announced on 27 January 2020 his intention to carry out a phased approach to reforming the scheme.<sup>1540</sup> The first phase involved making one-off payments in January and March 2020, including (in March) to non-infected widows and widowers.<sup>1541</sup> In August 2020, he announced a permanent uplift of annual support rates in line with EIBSS, though without a special category mechanism.<sup>1542</sup>

At a further meeting with campaigners in January 2020, the Minister for the Cabinet Office, Oliver Dowden, acknowledged the lack of progress on parity since January 2019. Ministers proposed to “*write to the Devolved Administrations requesting urgent engagement at official level on proposals to achieve greater parity.*”<sup>1543</sup>

In the late summer of 2020, Penny Mordaunt as Paymaster General and sponsoring Minister of the Inquiry, wrote to the Chancellor of the Exchequer, Rishi Sunak, to explain the work being undertaken to resolve the remaining disparities in support between the schemes. She pointed out that the resolution of the disparities was “*one of the main requests of the victims and their families*”. Her “*strong belief*” was that “*it would be the right thing to do.*”<sup>1544</sup>

Penny Mordaunt wrote again to Rishi Sunak on 21 September 2020 providing the costings for providing parity of financial support and seeking his views “*on how this additional funding would be integrated best into the 2020 Comprehensive Spending Review.*” She wrote “*I*

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1538 Letter from Vaughan Gething and Julie Morgan to Caroline Dinenage 9 October 2019 WITN5665004. Thereafter Vaughan Gething felt that there had been no “*genuine ministerial engagement at all*” on the question of achieving parity, prior to March 2021. Vaughan Gething Transcript 20 May 2021 pp73-74 INQY1000120

1539 *New Decade, New Approach* January 2020 p9 WITN5570002

1540 Department of Health Northern Ireland *Infected Blood Payments Announced by Swann* 27 January 2020 WITN5570003, Submission from Seamus Camplisson to Richard Pengelly and Robin Swann WITN5570021, Written Statement of Robin Swann paras 3.4-3.5 WITN5570001

1541 Department of Health Northern Ireland *Infected Blood Payments Announced by Swann* 27 January 2020 WITN5570003, Department of Health Northern Ireland *Health Minister announces additional Infected Blood Payments* 23 March 2020 WITN5570006

1542 Department of Health Northern Ireland *Swann announces increased payments for infected blood* 30 August 2020 p1 WITN5570008

1543 Minutes of Infected Blood Roundtable meeting 28 January 2020 p7 EIBS0000698. Written Statement of Matt Hancock p6 WITN5704001. Samantha Baker agreed in her oral evidence to the Inquiry that by mid 2020 there had not been much progress over the previous year: “*the UK Government hadn’t been able to secure any additional funding so that there was a lack of progress as a result of that and things weren’t progressing as quickly as we’d expected ... So certainly we were hoping to move forward more quickly but there didn’t seem to be much in the way of updates from the UK Government about progress.*” Samantha Baker Transcript 18 May 2021 pp67-68 INQY1000118

1544 Letter from Penny Mordaunt to Rishi Sunak 13 July 2020 EIBS0000706

*cannot stress enough the urgency of taking long overdue action on financial support and compensation.*<sup>1545</sup>

A bid was submitted to the Spending Review that took place in autumn 2020 which incorporated the most generous aspects of support offered across the four nations.<sup>1546</sup> The Welsh government did not have sight of the final bid that went forward.<sup>1547</sup> That particular bid was unsuccessful, as the Treasury decided to do a one-year spending review because of the economic uncertainties caused by the pandemic.<sup>1548</sup>

By the end of 2020 there had been no significant progress or developments regarding the achievement of parity.<sup>1549</sup>

On 11 February 2021 Penny Mordaunt wrote to the Secretary of State for Health, Matt Hancock, setting out her view that resolving the disparities was “*a matter of justice*” and that the Government “*must find a way to fund this – either through existing budgets or by making a further approach to the Treasury.*”<sup>1550</sup>

On 25 March 2021 Penny Mordaunt announced that the UK Government would provide funding to enable broad parity of annual and lump sum payments between the four national schemes.<sup>1551</sup> These changes were backdated to April 2019. Equivalent statements were also made in Wales<sup>1552</sup> and Northern Ireland.<sup>1553</sup> A corresponding statement was not made by the Scottish Government as it was in a pre-election period but an indicative statement was provided on the SIBSS website and within the next newsletter.<sup>1554</sup> Changes to the schemes were made within the following few months.

This move towards greater parity gathered momentum in March 2021. Mairi Gougeon, the Minister for Public Health and Sport in the Scottish Government, referring to the weekly four nations’ meetings of health ministers, told the Inquiry that:

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1545 Letter from Penny Mordaunt to Rishi Sunak 21 September 2020 EIBS0000705. The question of compensation as raised in this letter is further addressed in the chapter on *The Government’s Response to Calls for Compensation 2020-2024*.

1546 Written Statement of Matt Hancock pp8-9 WITN5704001. The bid involved taking “*the most generous*” aspects of support offered across the four nations and applying these to EIBSS. The additional costs that would be incurred by corresponding changes to the other three schemes were not a part of the Department of Health’s bid, though had the bid been agreed it would have resulted in additional funding to Northern Ireland, Wales and Scotland through the Barnett consequential. For a table comparing the main elements of the four schemes as at 18 March 2021 see Written Statement of William Vineall p31 WITN4688055

1547 Written Statement of Vaughan Gething para 23 WITN5665001

1548 Written Statement of Matt Hancock p9 WITN5704001

1549 Samantha Baker Transcript 18 May 2021 pp73-74 INQY1000118

1550 Written Statement of Matt Hancock p9 WITN5704001. He was due to give evidence to the Inquiry three months later on 21 May 2021.

1551 Statement to UK Parliament by Penny Mordaunt 25 March 2021 WITN4066017

1552 Written Statement by the Welsh Government 25 March 2021 WITN5665006

1553 Written Ministerial Statement of Robin Swann for Infected Blood Financial Support 25 March 2021 WITN5570018

1554 Written Statement of Samantha Baker pp11-12 WITN0713015, Scottish Government *Scottish Infected Blood Support Scheme – payment changes: statement* 25 March 2021 SIBS0000129

*“I think the day before the meeting on 11 March we were made aware that it was going to be an issue on the agenda at that point, and then it was discussed at the meeting on 11 March when I think all ministers agreed that parity should be pursued. But then I don’t think there was much over the course of the next couple of weeks until about 24 March. So, well, a decision had been reached at that meeting that we’d work towards parity. We didn’t know exactly when that would be until there was a bit of a flurry in terms of the decision-making that needed to be made and needed to happen really quickly over the space of 23, 24 and 25 March.”*<sup>1555</sup>

The evidence of Liz Redmond, the Director of Population Health in the Northern Ireland Department of Health, was to similar effect, such that the announcement came as something of a surprise.<sup>1556</sup> Vaughan Gething told the Inquiry that by 4 March 2021, when there was a meeting of the WIBSS governance group, the Welsh Government had heard nothing substantive further about funding and how parity might be achieved, and that *“It all happened in a significant rush towards the end of March”*.<sup>1557</sup>

The changes made to EIBSS as a consequence of the announcement on 25 March 2021 were as follows:

- (a) an increase in the annual payments for bereaved partners to 100% of the payment their partners were receiving at the time of their death for the first year after the death, reducing to 75% in year 2 and in subsequent years, in line with the position in Scotland.
- (b) the lump sum bereavement payment moved from a discretionary £10,000 to an automatic £10,000 in line with the position in Wales.
- (c) the lump sum payment paid to a beneficiary with Hepatitis C stage 1 increased from £20,000 to £50,000 in line with the position in Scotland.
- (d) the lump sum payment made to a beneficiary with HIV became an automatic payment of £80,500.<sup>1558</sup>

In Scotland, the applicable changes were to increase annual payments for infected beneficiaries and bereaved partners, and to introduce a £10,000 lump sum bereavement payment for the families of those beneficiaries who had died since the scheme began.<sup>1559</sup>

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1555 Mairi Gougeon Transcript 18 May 2021 p63 INQY1000118

1556 Liz Redmond Transcript 19 May 2021 pp92-94 INQY1000119

1557 Vaughan Gething Transcript 20 May 2021 pp81-82 INQY1000120, Minutes of Wales Infected Blood Support Service Governance Group meeting 4 March 2021 p3 WITN4506025

1558 Statement to UK Parliament by Penny Mordaunt 25 March 2021 p1 WITN4066017

1559 Statement to UK Parliament by Penny Mordaunt 25 March 2021 p2 WITN4066017

In Wales, increases were made to the annual payments for infected beneficiaries, and to the payments and the length of payments for bereaved partners in line with the position in Scotland. Changes were also made to the lump sum payments for Hepatitis C and HIV.<sup>1560</sup>

In Northern Ireland, annual payments for non-infected bereaved spouses/partners were announced on 1 March 2021.<sup>1561</sup> On 25 March 2021, it was announced that lump sum bereavement payments, which had been made to spouses or partners under the scheme since 2017 were to be extended so as to be payable to the estate of the deceased where there was no living spouse or partner, in line with the position in England and Wales and a commitment was made to introduce enhanced financial support for Hepatitis C stage 1 at the same payment levels as England as soon as a system could be put into operation.<sup>1562</sup>

Furthermore, there was a commitment that any future changes to the national schemes would be subject to consultation between the UK Government and devolved administrations.<sup>1563</sup>

## Non-financial support provided by the schemes

The disparity between the schemes was not confined to the financial support provided. There were also differences in the types of non-financial assistance given to applicants.

### Help with obtaining medical records

There remains some difference between the four nations when it comes to documentation relevant to acceptance into the schemes. Applicants have to show that they have received blood or blood products. To do this they need their medical records. WIBSS and SIBSS are willing to assist potential beneficiaries to locate these during the application process:

- WIBSS: Alison Ramsey in her oral evidence explained that WIBSS would approach a health board on behalf of an applicant, seeking to obtain medical records.<sup>1564</sup>
- SIBSS: similarly, Martin Bell confirmed that SIBSS would do the same, speaking to the GP or health board to access records to support an applicant's claim.<sup>1565</sup>

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1560 Statement to UK Parliament by Penny Mordaunt 25 March 2021 p2 WITN4066017, Written Statement by the Welsh Government 25 March 2021 WITN5665006

1561 Department of Health Infected Blood Bereaved Have Not Been Forgotten - Swann 1 March 2021 WITN5570017

1562 Written Ministerial Statement of Robin Swann for Infected Blood Financial Support 25 March 2021 WITN5570018. Following consultation from October 2021-March 2022 to assess eligibility for Hepatitis C stage 1 (enhanced) payments, a proposal for the assessment of eligibility was developed in liaison with a working group and approved by Robin Swann. This allowed an applicant to self-assess the impact of their condition along with a requirement for a professional medical declaration. The new Hepatitis C stage 1 (enhanced) support was implemented on 6 July 2022. Letter from Liz Redmond to Karen Bailey 6 July 2022 WITN4936038

1563 Statement to UK Parliament by Penny Mordaunt 25 March 2021 p2 WITN4066017

1564 They were also prepared to allow an applicant to substantiate an assertion that they had received blood or blood products by looking at the clinical coding on the applicant's records in the absence of an entry referring to blood or blood products. Alison Ramsey Transcript 20 May 2021 pp135-136 INQY1000120

1565 Martin Bell Transcript 18 May 2021 pp143-147 INQY1000118



In contrast, Brendan Brown confirmed that EIBSS expected the applicant to obtain supporting medical records themselves, albeit after appropriate signposting. It was the view of the administrators that the records contained personal confidential information and therefore the individual was best placed to pursue that.<sup>1566</sup>

### **In-house rights advisers**

Neither EIBSS, SIBSS, nor the scheme in Northern Ireland employ welfare and benefits advisers in-house. EIBSS and SIBSS do however signpost beneficiaries to an independent specialist adviser in welfare rights and social policy, reimbursing their invoices directly.

WIBSS is unique in having established a dedicated support service operated by welfare rights advisers and including a dedicated website with information and signposting. This team offers support with completing WIBSS forms, assistance with how to gain the supporting medical evidence required, as well as a broader service which provides:

- specialist benefit advice provided by welfare rights advisers;
- a direct line of communication between the welfare rights advisers and the Department of Work and Pensions and/or His Majesty's Revenue and Customs;
- advice on budgeting;
- advice on energy efficiency;
- advice on housing costs;
- advice on inheritance; and
- advice on accessing medical and/or social care and support.<sup>1567</sup>

### **Bespoke psychological support**

One important aspect – considered in the Second Interim Report of the Inquiry<sup>1568</sup> – is that those infected and affected should be able to access bespoke psychological support. Eventually, an announcement has been made that England will follow the lead of the other three nations in providing this.<sup>1569</sup> Wales is the only nation to provide this through their support scheme as part of their holistic approach to supporting people infected and affected. Lynne Kelly said of the Welsh approach:

*“Many of the infected and affected victims had experienced difficulties accessing financial support from the Macfarlane Trust, Skipton Fund and Caxton Foundation.*

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1566 Brendan Brown Transcript 21 May 2021 pp33-34 INQY1000121

1567 Written Statement of Alison Ramsey paras 29-32 WITN4506029, Alison Ramsey Transcript 20 May 2021 pp153-177 INQY1000120

1568 For the provision in Northern Ireland, Scotland and Wales and the policy development in England see Infected Blood Inquiry Second Interim Report 5 April 2023 pp63-79 INQY0000453

1569 Hansard House of Commons debate on Infected Blood Inquiry: Government Response 18 December 2023 RLIT0002341

*Their additional stress and suffering was a direct result of the way they had been treated by various scheme administrators. In Wales we had a clear vision of the threshold to be achieved to provide an acceptable service for beneficiaries ... the need for a tailored, holistic approach with psychological support and welfare and benefits advice for both the infected and affected.”*<sup>1570</sup>

## Experience of the schemes

How have the national schemes been regarded by those whom they exist to support?

A number of witnesses remained unaware that financial assistance was available, notwithstanding the establishment of national schemes. Colin Aspland stated: *“I have not received or sought any financial assistance from any of the Trusts and Funds set up to distribute payments. Indeed, prior to this witness interview, I had no idea that such Trusts and Funds were in existence.”* Since giving his statement Colin has died.<sup>1571</sup>

Beyond some lack of awareness about the schemes, the English scheme seems to have been more difficult to engage with than the Scottish, Welsh and Northern Irish schemes.

Differences between the schemes can be seen in how they assess their own work. SIBSS conducted customer satisfaction surveys in 2018, 2020 and 2023, with 97% of respondents rating the overall service as good or very good in 2023.<sup>1572</sup> WIBSS conducted a survey in 2021, with 75% of respondents rating the overall service as good or very good.<sup>1573</sup> EIBSS did not publish the results of a survey they conducted in 2022, just the headline that 92% gave an overall rating between 7 and 10 out of 10.<sup>1574</sup> EIBSS’ and WIBSS’ key performance indicators are published but do not include any measure of customer satisfaction.<sup>1575</sup>

### English Infected Blood Support Scheme (EIBSS): some experiences<sup>1576</sup>

Samantha May, who manages the Hepatitis C Trust helpline information and support service reports that around one in ten of their contacts from people infected through blood and

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1570 Written Statement of Lynne Kelly p29 WITN3988001

1571 Written Statement of Colin Aspland para 34 WITN0900001

1572 SIBSS 2023 Customer Satisfaction Survey p3 RLIT0002351. The response rate was 66%. SIBSS 2020 Customer Satisfaction Survey and 3-year Review of Service WITN4728013, SIBSS 2018 Customer Satisfaction Survey Final Report WITN4728024

1573 WIBSS Customer Satisfaction Survey Results 2021 pp1-2 WITN4506031. The response rate was 42%.

1574 EIBSS Annual Report 2022-23 p7 RLIT0002223. The response rate was 56%.

1575 EIBSS Annual Report 2022-23 p8 RLIT0002223, WIBSS Annual Report 2021-22 p25 RLIT0002352

1576 In response to the criticisms being put to NHS Business Services Agency under the Inquiry Rules 2006, Brendan Brown said *“NHSBSA (EIBSS) are sorry to read the challenges which some people feel they have experienced with accessing support from the scheme. We make every attempt to assist people with their specific requests, learn from feedback and improve processes, where possible ... I would like to state that several of the witness statements are several years old, and in some cases there have been improvements made which already address the criticisms, so they no longer present a challenge to beneficiaries/applicants.”*

blood products concern the support schemes, predominantly EIBSS.<sup>1577</sup> She provided case studies of the considerable number of hours spent by the Trust supporting people seeking to access support from EIBSS.<sup>1578</sup> She told the Inquiry:

*“From the beginning of my time on the helpline, I have been constantly surprised that many who received infected blood/blood products were not made aware of the fact that they were able to claim from these funds immediately after their diagnosis, or in many cases, at some point even many years later ... Many feel very angry that they weren’t made aware of the scheme earlier ... But many people we deal with are elderly, extremely unwell, do not use the internet, or have no family support to help them do so and they remain totally unaware that they exist ... Even for those who do find out about the schemes, the language used and level of detail required on any of the blood support scheme application forms, past and present, is for some, so onerous that many people feel like it is making a claim for benefits or intrusive, which they describe as feeling ‘daunting’ or ‘degrading’ ... Whilst the process is a clear barrier to all applying, without question the single biggest barrier to people who received infected blood making a successful claim is the difficulty in finding their medical records ... the people facing the biggest barriers to a successful application are those with the least resource, the least health literacy, and without the means to pay for private medical time and/or legal advice. These are often the people who need the financial support the most.”<sup>1579</sup>*

Kathleen Locke “accidentally found out” about EIBSS in 2020 and “then had to support my mother to apply to the fund as without my help she would have been unable to do so. My mother is not computer literate and is unable to access online meetings, emails or websites.”<sup>1580</sup>

Bureaucratic hurdles have caused difficulties for other people. Benjamin Griffiths who was infected with Hepatitis C through a blood transfusion after an accident as a child, recounts:

*“I recently made an application to the England Infected Blood Support Scheme (EIBSS) in late 2022. I found them unhelpful during my initial contact and I was given conflicting advice as you don’t get to speak to the same person. So, there is miscommunication because you have to deal with so many people. So far, I*

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1577 Written Statement of Samantha May para 230 WITN0912001

1578 Written Statement of Samantha May paras 115-176 WITN0912003

1579 Written Statement of Samantha May pp47-49 WITN0912001. In response to the criticisms being put to NHS Business Services Agency under the Inquiry Rules 2006, Brendan Brown said “*The EIBSS thanks the Hepatitis C Trust for providing such an important set of information and experiences to the Infected Blood Inquiry. The EIBSS will consider whether there are any points that have been raised which directly relate to our current administration ... to fully understand what we may be able to change in the future.*” Noting that EIBSS are administrators of the scheme, he said “*We may therefore find that the majority of the challenges faced by beneficiaries/applicants are not included within the DHSC scheme specification and therefore unable to be provided by the EIBSS. However, we are keen to understand where this is the case, as we will always put these matters to DHSC for consideration of making informed changes to the DHSC scheme specification.*”

1580 Written Statement of Kathleen Locke para 64 WITN0049001

*have spoken to 5 different people who appear to be Assessors and I have been given no constant point of contact. As a result, I have been given different advice and different requests from the [different] EIBSS employees.”<sup>1581</sup>*

One man received a first payment from the Skipton Fund but nothing more and was at first unaware of EIBSS. He was told by EIBSS that he “*had fallen through the net. No explanation or apology was offered for this. They said I wasn’t the only one to have been ‘forgotten’ in this way and that they would resolve it ... Had I not contacted the Inquiry I would never have known.*”<sup>1582</sup>

There remain problems in relation to producing enough evidence to show a causative transfusion, because of a lack of medical records. Maria Mooraby’s application, and subsequent appeals to EIBSS, were refused. Her treating clinician provided a detailed letter to EIBSS explaining why he considered it most likely that she had contracted Hepatitis C from a blood transfusion in 1989 after surgery for a ruptured appendix associated with sepsis. Despite having written statements from her husband and daughter which described her receiving blood, EIBSS rejected her application.<sup>1583</sup>

Andrew Bragg had a road traffic accident in Norway and was treated in both Bergen and the UK. His application to EIBSS was rejected as was his appeal:

*“From Liverpool I obtained fragmentary records concerning treatment between September 1986 and February 1987. East Lancashire Hospitals Trust responded saying they had no records of my treatment as these had been destroyed in line with hospital policy. There was therefore no way I could then gather a detailed description of my treatment when under the care of these institutions to support my application from the information provided. [The Bergen Hospital] responded by saying that all four blood donors [in Norway] had been repeatedly tested and were all HCV negative ... My appeal to EIBSS was rejected on the grounds that I cannot prove that the infection was as the result of NHS actions ... Any chance I may have had of proving this causal link has been compromised by the retention of only a limited amount of personal data by one hospital and the destruction of all of my files by another. As a result of the actions of these NHS organisations and given the terms of reference of the EIBSS assessment panel then I have no ability to prove my case.”<sup>1584</sup>*

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1581 Written Statement of Benjamin Griffiths para 51 WITN7367001

1582 Written Statement of ANON paras 59-60 WITN7391001. In response to the criticisms being put to NHS Business Services Agency under the Inquiry Rules 2006, Brendan Brown said “*The EIBSS is aware that up to 460 people may not have been informed by the Alliance House Organisations (AHOS) of the transfer to the EIBSS in November 2017.*” As explained in his statement, these records were not transferred to EIBSS due to explicit consent being sought by the Alliance House Organisations prior to any record being transferred to EIBSS. See Written Statement of Brendan Brown para 25 WITN4496001

1583 Written Statement of Maria Mooraby paras 11-14 WITN6155006. She had not, prior to giving her statement to the Inquiry, heard of either Skipton or EIBSS. Written Statement of Maria Mooraby paras 54-55 WITN6155001

1584 Written Statement of Andrew Bragg paras 61-67 WITN0195001

Another woman's application to EIBSS was refused because she did not have sufficient medical records:

*“Included in my application was a copy of proof of HCV, a letter from a friend who visited me in hospital in 1982, and documentation from my GP which supported my application. What was not in the application was my medical notes from St Luke's Hospital, now the Royal Surrey County Hospital, which I have been unable to obtain. I was told that there was no record of my operation in 1982 and that these records had been destroyed in 2015 because the hospital was going digital. They informed me that because I had not recently received treatment at the hospital, my records would not have been kept. On 5 March 2019 the EIBSS responded asking for more information about the blood transfusion and the operation. By chance, I had an appointment with my liver specialist on 6 March 2019, at the local hospital. She managed to print off the relevant parts of my medical history. I have submitted all the information about my operation and blood transfusion, including photographs of my scar. I have also sent redacted paper records held by my GP which confirms my ruptured ectopic pregnancy in 1982. I have also sent a photocopy of my daughter's birth record which confirms that a fallopian tube was removed, and also details my blood group ... My application has been declined on the grounds that I had no proof of a blood transfusion in 1982. There is proof that I had a ruptured ectopic pregnancy and that I am in the database at the Royal Surrey Hospital, but they have destroyed the medical records held by them. There is no record of me having the blood transfusion, but I have been told by doctors that it is highly unlikely that an individual would not need a blood transfusion after suffering from a ruptured ectopic pregnancy.”<sup>1585</sup>*

Ronald Edge felt the application process for the special category mechanism has been complicated and unclear:

*“While I received the lump sum payments from the Skipton Fund and now the EIBSS fairly easily, it was much more difficult to access the monthly top up payments that I am now receiving. The paperwork involved was complex and difficult to understand. From the first correspondence my wife and I received from the EIBSS, the form attached made it look as though I would not be eligible to apply for monthly top up payments. When I mentioned it to my brother, he suggested that I pursue it as he said that I should be eligible. My wife and I then requested further forms and information from the EIBSS. We received multiple forms and were told that I was not eligible for the top up payments initially. It took further persistence and correspondence to receive the right form and make sense of it. After receiving the correct form I realised that I was eligible to apply for top up payments ... If my wife and I had accepted the first form and letter we*

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1585 Written Statement of ANON paras 7.6-7.7, para 7.14 WITN0877001

*had received from the EIBSS, we would not have realised that we were eligible for top up payments and would not have been able to access that money.”<sup>1586</sup>*

Ronald has died since giving his statement.

Another man describes:

*“Applying to EIBSS for payment under the Special Category Mechanism was quite different [to Skipton for a stage 1 payment], and rather off-putting. It appeared to require a very high level of illness to qualify for payment, and there was little indication of how the decision would be taken as to whether to award the payment or not. I read the information I was sent by EIBSS and I decided not to apply. I later changed my mind after receiving a phone call from a specialist nurse at the Haemophilia Centre to ask me whether I had applied yet. She advised that I should.”<sup>1587</sup>*

He attended an appointment with the Centre’s social worker and specialist nurse who helped him with the application form and his application was successful.<sup>1588</sup>

Even where support was previously received from the Macfarlane Trust and Skipton Fund, difficulties arose in applying to EIBSS. One woman had to reapply and provide evidence that she and her husband were together at the time of his death from liver failure: *“I sent them a copy of his death certificate and marriage certificate. I found the system difficult and onerous and I could not fully understand why I had to submit all the information they required. I also had to get my father-in-law ... to sign a form to verify we were together before and at his death. They needed proof that we were living together and I couldn’t understand why.”<sup>1589</sup>*

Jackie Britton, a campaigner, describes the difficulty of knowing what support is available:

*“Things have improved a little and EIBSS do now publish a booklet ‘Discretionary Support Guidance Booklet’, giving information on the sorts of financial assistance available, such as income top-up payments, accommodation adaptations, respite, etc. When changes are made this does get updated, but sometimes not very quickly, and EIBSS can be slow too in updating application forms. It is very frustrating for beneficiaries to spend time completing forms only to be told a form is now out of date. I have asked that they keep their website as up to date as possible, to help people access the correct information. So many of those infected are ill and suffer from brain fog, so the process should be made as user-friendly as possible.”<sup>1590</sup>*

Su Gorman told the Inquiry:

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1586 Written Statement of Ronald Edge paras 60-63 WITN0257001

1587 Written Statement of ANON paras 123-124 WITN0369001

1588 Written Statement of ANON paras 125-126 WITN0369001

1589 Written Statement of ANON para 78 WITN1437001

1590 Written Statement of Jackie Britton para 86 WITN1838006

*“I made a first attempt at tackling the forms I had received from EIBSS which were purportedly in relation to the bereavement payment and top up payment. On the list of necessary documents was a request for proof of cohabitation up to the point of death with the suggestion that confirmation by a referee might be necessary. Less than a month after holding Steve’s hand as he breathed his last breath and ended our 44 year union I felt that I could not go on ... I found the wording of the forms that I had to complete insensitive. There were references to ‘you and your partner’s income’ or ‘household income’. I had just lost my husband and my home. It was heartbreaking ... Meanwhile I was also asked for a form for a funeral grant. This included the questions ‘why do you want this money?’ and ‘what are you going to do with it?’”*<sup>1591</sup>

The restrictions on EIBSS financial assistance also remain problematic. One man, infected with Hepatitis A, Hepatitis B and Hepatitis C, states that:

*“It is disgusting that the financial assistance [from EIBSS] is means tested and that my wife’s earnings are taken into consideration when assessing the level of financial assistance that I am entitled to. It is wrong because being infected with HCV has significantly affected my ability to work as a self-employed bricklayer, particularly in winter months ... if I do not work, I cannot get paid, meaning that my HCV infection directly affects my income. I believe the financial assistance scheme should not take my wife’s earnings into account, as my financial situation has been affected by my HCV infection irrespective of my wife’s income.”*<sup>1592</sup>

Simon Gittons says the day-to-day operations of EIBSS have *“been unreliable. I have never received the correct payment despite promises that the correct amounts would be made to me. This has been yet another unnecessary cause of stress.”* Like others he says: *“There is also no guarantee that I will continue to receive payment and this is a big concern for me.”*<sup>1593</sup>

Some feel that the attitude of EIBSS continues to be demeaning and unfair. Michael Gower uses a wheelchair and says: *“A while ago, I wanted a mobility scooter but was required to show proof that I needed it. I was required to get reports from consultants to prove that it was a necessity for me. It was a hassle to apply for it and to go and see them. It was quite intrusive.”*<sup>1594</sup> Another man describes EIBSS as *“another label hanging around my neck. It advertises my issues about blood. I spoke to someone at the scheme and he said there was nothing they can do despite many people raising this concern.”*<sup>1595</sup>

One man, who also received support from the Macfarlane Trust, says: *“The process of applying to the EIBSS was and is still time consuming, demoralising, difficult, dependent on*

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1591 Written Statement of Su Gorman para 23, para 39, para 41 WITN2753003

1592 Written Statement of ANON paras 80-82 WITN0376001

1593 Written Statement of Simon Gittons paras 40-41 WITN1236001

1594 Written Statement of Michael Gower para 43 WITN1748001

1595 Written Statement of ANON para 33 WITN1081001

*haemophilia centre support and although an improvement on the MFT, extremely unfair.*<sup>1596</sup> Diane Thiang Su Todd who was infected through her ex-partner feels the change to EIBSS brought no improvement: *“things have been worse since then. There is no longer any personal contact and I feel that I am just a number.”*<sup>1597</sup>

### **Welsh Infected Blood Support Scheme (WIBSS), Infected Blood Payment Scheme for Northern Ireland and Scottish Infected Blood Support Scheme (SIBSS): some experiences**

It seems that there have been fewer problems with the way that WIBSS, the scheme in Northern Ireland and SIBSS have been administered.

Karisa Jones has found the process of applying for financial assistance from WIBSS *“straightforward, the WIBSS are very helpful. I have asked WIBSS for help with putting in a disabled shower downstairs and am waiting to hear whether they will help me. They ring me to keep me updated ... In terms of the amount of financial assistance we have received, how can you put a price on someone’s life? We are struggling.”*<sup>1598</sup>

One man said in 2019 *“In terms of the amount of financial assistance received, I would have appreciated more, especially from the Welsh Government. It would be good if it was for life.”*<sup>1599</sup> Margaret Fitzgerald said the WIBSS support *“would have been of greater benefit to me much earlier in my illness to pay for various things including taxis when I was too ill to walk.”*<sup>1600</sup>

Rita Kirkpatrick told the Inquiry that her husband received a letter about the new scheme in Northern Ireland but he then *“received no further information”* and it was *“very difficult to find out information about the new scheme.”*<sup>1601</sup>

Gary McKelvey told the Inquiry about the difficulties accessing support in Northern Ireland for his bereaved mother because his father’s medical records had been destroyed. *“I spoke with [the scheme manager] and ... he was very helpful on the phone, which was the first time anyone had been helpful. But ultimately he was only able to come back with the same response: no medical records, there was no way forward”*. He was advised that his mother should contact her Assembly Member which led to the Permanent Secretary advising that he should contact the scheme manager: *“Once again, I had hit a brick wall and I was right back at square one again”*.<sup>1602</sup>

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1596 Written Statement of ANON para 59 WITN1005001

1597 Written Statement of Debra Thiang Su Todd para 129 WITN1565001

1598 Written Statement of Karisa Jones paras 49-50 WITN2019001

1599 Written Statement of ANON para 43 WITN2002001

1600 Written Statement of Margaret Fitzgerald para 7.4 WITN0050001

1601 Written Statement of Rita Kirkpatrick para 44 WITN2921001

1602 Gary McKelvey Transcript 26 September 2022 pp44-48 INQY1000246, Written Statement of Gary McKelvey para 41 WITN0525001



With SIBSS, the decision of whether to select “moderately” or “severely” affected when completing the forms for further payment was not altogether straightforward for some people. Graeme Malloch says that *“I did select moderately affected when I was filling in the form. I did not think I could fully justify severely but I am unsure about this. There seems to be a big jump between the two.”*<sup>1603</sup>

Nevertheless, the money has still been too late. As Margaret Cooper, who applied to SIBSS, says:

*“It was a straightforward process. We just filled out some forms and posted it off. Audrey [my daughter] helped us. One phone call to the bank and the money was in. We never had any problems ... Audrey says there are new things coming out that we should be entitled to but you cannot put a price on this. What is the price for his health? What is the price for everything I have done? What is the price of any of it? Ricky [my husband] at least deserves enough for a good quality of life but he will never get it now.”*<sup>1604</sup>

Since Margaret gave her statement, her husband has died.

Feyona McFarlane explains that the SIBSS money *“doesn’t really change that I should have had a pension, a house bought and paid for, and some ‘normal’ relationships. I think that as I approached 60 years old it began to sink in that I had none of these things and the impact that would have on my old age. I have no house to sell and downsize, no private pension and no prospect of change.”*<sup>1605</sup>

Rosemary Wright has commented (reflecting on a disparity with EIBSS at the time she wrote it) that: *“the Scottish Scheme has made a huge difference and has had a real impact on our life. It is just another example of how this Inquiry has been long overdue, as I am aware that the same support is not available in England.”*<sup>1606</sup>

## Commentary

Although there have been a number of criticisms of the national support schemes, there is little doubt that the decision no longer to fund the Alliance House Organisations and to transfer their functions to new national schemes was inevitable. Reform presented a chance to improve provision, and the way it was distributed. Scotland and Wales took particular advantage of this. In Scotland this was by introducing ongoing support for bereaved partners and adopting a system of self-declaration that the symptoms of Hepatitis C and its mental health impacts had grown appreciably worse without yet meriting a “stage 2” award. This allowed for enhanced payments to them. Wales introduced more holistic support to people

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1603 Written Statement of Graeme Malloch para 48 WITN2192001

1604 Written Statement of Margaret Cooper paras 62-64 WITN0306001

1605 Written Statement of Feyona McFarlane para 50 WITN1935001

1606 Written Statement of Rosemary Wright para 38 WITN2286001

infected and affected. Both seem to have worked well, and to have avoided some of the worst attributes of the Alliance House Organisations.

There is little doubt, too, that the additional funds provided by all governments have been welcome – though since the circumstances giving rise to the infections arose when there was no devolved government, the problem should have been viewed from the outset as a UK problem, and steps taken to arrange broad parity<sup>1607</sup> of provision between the schemes.

That said, there are two significant areas where the response of governments fell short. The first is the time it took to rationalise the schemes, given what was increasingly apparent about the unsatisfactory ways in which they had been functioning.<sup>1608</sup> It had been recognised by Anna Soubry in early 2013 that ways in which the schemes were operating were unacceptable, but she realised that the problems were more deep-seated, and needed reform – given political will to do it. People were not only being poorly served, but the way in which the schemes had operated often exacerbated their condition. It took until 2017 to deal with them. In the interim, a backbench debate and the APPG report in Parliament, and the campaigning of the Haemophilia Society and campaign groups outside Parliament, occurred. Though it takes time to arrange for a consultation about the nature of any change, and consider the responses to it, four years was too long. Responsibility for this delay lies with the Department of Health.

The second is that the way in which the schemes were set up meant that there were significant disparities from the outset. The support provided was a response to what was a problem general to the UK, the seeds of which were sown long before any devolution of government. The Alliance House schemes had operated cross-border, though Skipton support after 1 April 2016 differed to some extent in each nation. However, when the Department of Health consultation was carried out on changes to the schemes, that consultation and the consequent decisions occurred without notice to or involvement of the devolved administrations. Wales and Northern Ireland were left with no real alternative but to set up their own schemes, which was responsible for some of the disparity. It is, of course, inherent in devolution that each nation of the UK had and has the right to determine for itself what health policy should be, and was thus constitutionally free to differ. Nonetheless, it is part of belonging to a larger unit (the UK) that, though each nation could go its own way, where common issues cross the borders there should be an attempt at joined up planning from the outset. It did not happen at the start. It took too long thereafter to achieve a reasonable degree of parity. If, as seems more likely than not, it was the external pressure of the Inquiry beginning to hear evidence in April 2019, or the Secretary of State for Health and Social Care being about to give evidence in 2021, that led to the timing of announcements of

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1607 One reason for devolution is to ensure that local circumstances are reflected better in decision making: it is possible they may lead to slightly different emphases in provision in each of the home nations if their national arrangements better fit their populations. Hence the expression “broad parity” – in effect, ensuring exact parity of provision unless there are circumstances in the particular home nation which in the opinion of its executive or legislative body compel some difference of provision to be made.

1608 See the chapters on the *Macfarlane Trust*, *Eileen Trust*, *Skipton Fund* and *Caxton Foundation* which precede this.

improvements in the schemes which brought about much closer concordance of one with the other, then it is highly regrettable that that should have been the case rather than the issue being addressed at the outset. Responsibility for this lies with the departments of health, principally the Department of Health in Westminster.

As well as the self-evident financial impact of disparities, the lack of parity has itself exacerbated the psychological damage to individuals. As Dr Caroline Coffey, a consultant clinical psychologist with WIBSS, explained in a letter to the Welsh Government:

*“It is crucial that the context and impact of the decisions of a higher powered organisation are seen as relevant and need consideration. There are similarities between the decisions of the governments now, and the NHS then, which is a reminder of the harm not help that was inflicted upon the beneficiaries.*

*Understandably people report entrenched feelings of anger and injustice, alongside damaged identities related to feeling like ‘a second-class citizen’, as unworthy and undeserving ... The extent of the psychological injury is unquestionable. The acceptance and normalisation of the harm caused is only more recently being exposed and challenged but the current legitimisation of the lack of parity is a highly sensitive reminder that again such people are targeted as ‘less than’ causing secondary psychological injury.*

*The inequality provokes reactivation and reliving of past traumatic experiences ... Achieving parity would demonstrate the importance of recognising the need for fairness and justice. I have been struck by the resourcefulness and resilience shown by the beneficiaries of the scheme and surprised by the desire to ‘move forward’ from such painful experiences. Realistically the associated traumas will never be resolved but it is a psychologically damaging and limiting process if aspects of inequality, in particular the lack of financial parity across the four devolved schemes are not currently addressed.”*<sup>1609</sup>

The provision of bespoke psychological support has been one area in which Scotland, Wales and Northern Ireland have given a lead, and there has not yet been even broad parity of provision between them and England. It is a matter of regret<sup>1610</sup> that despite calls over the past five years – from psychologists themselves, campaigners and from this Inquiry – it has taken as long as it has for England to be on the point of following their lead.

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1609 Letter from Dr Caroline Coffey to Catherine Cody 11 March 2021 WITN4506014. Dr Sarah Meekin, the head of psychological services within the Belfast Health and Social Care Trust, echoed this in her oral evidence to the Inquiry: “we often hear people talking about people feeling like lower-class citizens in terms of how they feel that they were treated, and any lack of parity contributes to those feelings and to that experience, and so that has a sort of ongoing psychological impact as well”. (Dr Sarah Meekin) Specialist Psychological Support Expert Panel Transcript 11 November 2022 pp105-106 INQY1000260

1610 For reasons which are set out more fully in the Second Interim Report of the Inquiry. Infected Blood Inquiry Second Interim Report 5 April 2023 pp77-79 INQY0000453

## 6.12 Access to Treatment

This chapter explores some of the difficulties which people have experienced in accessing medical treatment. It looks at four areas: the lack of access to specialist treatment; the availability of treatments for Hepatitis C; palliative and end of life care; and the availability of recombinant factor products.

### Key Dates

**November 1994** alpha interferon is licensed for the treatment of Hepatitis C in the UK.

**1994 - 2000** patients report difficulties accessing alpha interferon treatment.

**October 1996** UKHCDO confirms recombinant Factor 8 as the safest product available for the treatment of people with bleeding disorders.

**1997** Wales adopts policy of recombinant Factor 8 for all Haemophilia A patients.

**26 February 1998** Secretary of State for Health announces that recombinant products are to be made available for all children under 16 and previously untreated patients in England.

**2000** goal for patients in Scotland and Northern Ireland to have recombinant treatment, achieved in 2002 and 2003 respectively.

**January 2001** commitment for recombinant Factor 8 to be available for adult patients in England on a phased basis over 4-5 years, achieved in 2004/2005.

**August 2002** *Hepatitis C Strategy for England.*

**October 2000** NICE recommends alpha interferon and ribavirin combination therapy for the treatment of moderate to severe Hepatitis C.

**May 2001** Haemophilia Society leads campaign for full access to recombinant Factor 8.

**June 2002** pegylated interferon monotherapy is licensed in the UK.

**September 2006** *Hepatitis C Action Plan for Scotland.*

**January 2007** *Action Plan for the Prevention, Treatment and Control of Hepatitis C in Northern Ireland.*

**August 2007** *Blood Borne Viral Hepatitis Action Plan for Wales.*

**2011** DAAs are licensed and become available for Hepatitis C treatment in the UK.

**2014** the main treatment for Hepatitis C becomes sofosbuvir combined with other agents.

### Abbreviations

**DAA** Direct-acting antiviral

**NICE** National Institute for Health and Care Excellence (formerly known as the National Institute for Clinical Excellence)

**UKHCDO** United Kingdom Haemophilia Centre Doctors' Organisation

## Introduction

Where harm has been done, it might be thought that, as a matter of justice, the state should do all that it reasonably can to alleviate the consequences of that harm. With that thought in mind, this chapter examines four aspects of medical treatment so as to assess whether the state (for these purposes, essentially the National Health Service (“NHS”)) did do all that it reasonably could, or whether in fact the harm already sustained was compounded by difficulties in accessing appropriate care and treatment.

The four aspects of treatment which are explored below are: lack of access to specialist treatment; the availability of treatments for Hepatitis C, palliative and end of life care; and the availability of recombinant factor products. The last is relevant only to people with haemophilia.

### Lack of access to specialist treatment

The first question is: should people with bleeding disorders who became infected have been treated by doctors both expert and experienced in hepatology (for hepatitis) or by those whose regular task it was to deal with HIV – or by a multidisciplinary team including such expertise – rather than doctors whose expertise lay in the treatment of bleeding disorders.

The answer to that question is obviously yes. It is exactly what would be likely to happen in the case of those infected with Hepatitis B or C where the cause was a transfusion, and it is clear from the evidence which the Inquiry received that it was a matter of considerable concern for people with bleeding disorders that the same answer was not regularly given in their case. Their own words speak for themselves.

*“They were out of their depth ... it just seemed a bit weird, the director of haemophilia was trying to give us this drug [AZT] no-one knew very much about as a trial and it was just all very scary.”*<sup>1611</sup> So said Mr AK of his haemophilia centre: they were attempting to treat the HIV he had suffered, but their main specialism was in haematology.

One woman describes that *“It took about six years before [my husband] saw a Virologist and to find out how far the HIV virus had progressed. We were always worried as we didn’t know what was happening.”*<sup>1612</sup> Another woman says *“The Genito-urinary and Sexual Health Clinic served all HIV patients with the exception of the haemophilia patients with HIV, who were ring-fenced within the haemophilia centre ... [My husband] was denied the benefit of HIV specialists discussing his treatments with him.”*<sup>1613</sup>

Another man was infected with HIV in 1981, when he was seven, and his parents were not informed of his infection until 1988, when he was 14. He says *“After my parents were told*

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1611 ANON Transcript 11 October 2019 pp163-165 INQY1000040

1612 Written Statement of ANON para 6.3 WITN2552001

1613 Written Statement of ANON para 41 WITN5406001

*about my HIV diagnosis, it took another year before I saw a specialist ... By this point I had developed AIDS ... He got me on HIV drugs straight away and basically saved my life.*"<sup>1614</sup>

Paul, who gave evidence anonymously, said about the lack of specialist input into his HIV care *"Just because his haemophilia patients had developed HIV he suddenly hadn't developed a specialism in HIV himself ... It never really sat well with me"*. Then a new doctor came and set up a review clinic and there was an opportunity to see a psychologist. *"It was the best help I had had from anybody at that point. It was the first time I had actually had to talk about it. She was aware that none of us had actually spoken to anybody else about it so she set this little support group up ... We met once a month ... We felt safe ... It was incredibly sad, people's stories. However, I don't think I'd be here today if it wasn't for those people ... I developed those tools of survival."*<sup>1615</sup>

Brian Ahearn had a similar concern about his treatment for Hepatitis C: *"I should have been referred to a hepatologist straight away"*.<sup>1616</sup> His haemophilia clinician, Professor Charles Hay, said *"In the late 1990s and early 2000s, we had only one consultant hepatologist ... a very common situation in the NHS ... Generally at that time the hepatologist would offer advice and refer the patient back to us for further management."*<sup>1617</sup>

Robert James told the Inquiry:

*"the way haemophilia doctors saw us ... we were their 'children'. Because it was predominantly a young person's disease at the time because older haemophiliacs had died of bleeding before we had cryo, there was an awful lot of young children, and for haemophilia doctors, they saw us like that. And so they would just not refer us on to an appropriate immunologist ... my girlfriend at the time, it made sense for her to have an HIV test, and we had to go to a GU clinic cause the Haemophilia Centre wouldn't do it. And we saw a GU doctor, and he sort of registered her as a patient, and he would have treated her. And my haemophilia doctor ... would treat me and I wouldn't be allowed to go and use them. I don't know why, when we'd always had orthopaedic surgeons in there. That was routine to have a joint clinic with them. Why not have a joint clinic with the next specialism? ... And if you were a doctor that treated people, an infectious disease doctor, an immunologist, whatever it was, you'd be seeing lots of that and you'd be getting better and better, and you'd be going to conferences to talk to other doctors about that. Haemophilia doctors almost -- just didn't seem to do that and a lot of them -- there were a couple I mention, Mark Winter was one and later on Has Dasani was very good at keeping up-to-date with knowing what was going on, but the others, they just seemed to work on the idea 'Well,*

1614 Written Statement of ANON para 6, para 10 WITN2149001

1615 Paul (ANON) Transcript 10 October 2019 p48, pp44-46 INQY1000039

1616 Written Statement of Brian Ahearn para 30 WITN0165001. Since giving his statement Brian has died.

1617 Written Statement of Professor Charles Hay p9 WITN3289006. Professor Hay also said that because they had a different funding mechanism they were able to offer pegylated interferon and ribavirin therapy several months before it became available in hepatology.

*I'll read a few papers and then I'll know what to do. Then later when we got combination therapy, there was a particular issue with haemophilia doctors, and I know it was at my centre, and I suspect it was at a number of others, they were just so behind. So they were prescribing one drug on its own, which at the time was not just useless, it was unethical.”<sup>1618</sup>*

By contrast Mr AM said: *“The haemophilia doctors at Great Ormond Street, I understand from my mother, were incredibly proactive about getting that care ... they got a specialist HIV doctor in from the Mortimer Market Centre, and they set up a specialist clinic for all the boys at Great Ormond Street who were infected to be treated and looked after and to fight to get the first medication.”* At the end of his evidence he talked about what might have been:

*“Haemophiliacs should have been systematically tested and a comprehensive look-back exercise undertaken to ascertain those infected from the whole blood community. Specialist clinics should then have been developed with the leading experts treating those infected, experts in HIV, experts in hepatitis, counsellors, dentists and anything else the infected were struggling to cope with. Had that happened, I firmly believe many more people could have ended up in my position, namely having been able to lead a fulfilled life, despite the devastating infection which had befallen them ... I believe I am an example of what could have been achieved had a coordinated and comprehensive response been instituted.”<sup>1619</sup>*

Treatment of HIV or hepatitis by haemophilia centres also had the consequence that people who had been infected as a result of their treatments often had no choice but to be treated for that infection by the doctor or hospital who and which were responsible for what had happened to them, and in whom in many cases they had lost trust.<sup>1620</sup> The psychosocial expert group reported to the Inquiry that:

*“Breakdown in trust has been shown to have deleterious effects on quality of care across all serious health problems ... Patients need to have trust in their healthcare provider's ability and willingness to provide the best possible treatment. When this trust is compromised or damaged, communication is adversely affected, together with the patient's willingness to follow treatment or advice. While a few individuals were able to transfer to another healthcare provider, this did not usually happen. Consequently, having to continue attending for healthcare in the treatment setting where the infected blood had been given was clearly a major source of distress for many individuals.”<sup>1621</sup>*

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1618 Robert James Transcript 8 June 2021 pp19-22 INQY1000125

1619 ANON Transcript 15 October 2019 p100, pp110-111 INQY1000041

1620 It is well recognised in the courts that patients who have been harmed by clinical negligence should not be required to return to the hospital or surgery at which they suffered that harm, but may be funded to have the care which they may need as a result of it elsewhere, or privately. I say this because although the Inquiry makes no findings of negligence – it may not in law do so, and it is an inquiry not a court – the reason for this approach is that it is unreasonable to expect a person to return to the place in which they suffered ill treatment. That is generally a sound approach.

1621 Expert Report to the Infected Blood Inquiry: Psychosocial Issues January 2020 p7 EXPG0000003

The second question is a similar one, but is not confined to people with bleeding disorders. It is: should people who became infected as a result of their NHS treatment be treated for their infection by an appropriate specialist multidisciplinary team?

Again the answer is an obvious yes, but accounts given to the Inquiry have shown the variation in provision.

For example, Jackie Britton said that at one hospital *“you fought for your six-monthly scans, which could take eight months, and then it was a wait to see your consultant”* and contrasted this with her later experience: *“with King’s [College Hospital] you have the scan in the morning, you see the clinic in the afternoon.”*<sup>1622</sup>

Michelle Tolley said:

*“you have your scan, you might wait three or four weeks for a letter and then you see your hepatologist, if you’re lucky, and then you get sent off for bloods ... not like at King’s [College Hospital], where you have your scan in the morning, your bloods, and then you see the person in the afternoon. That’s all done and dusted. So this can be over a space of a month from having a scan to seeing a hepatologist ... then before you know it, you’re having another one ... it’s always there at the back of your mind ... So, yeah, it’s horrible and you have that twice a year and I’m going to have that until I’ve popped my clogs.”*<sup>1623</sup>

One woman who experienced treatment in different places said: *“Where I live, I can’t have the special liver scan which means that you don’t have to have a biopsy; the hospital doesn’t have that facility. This means I will have to keep going for biopsies every four years, to keep checking on my liver. The procedure is very painful.”* She asked to be referred to another centre, where she had previously been treated, but the request was declined.<sup>1624</sup>

Jean Smith’s doctor informed her that since he had a small department he didn’t have access to the treatments she needed. At a later appointment he said that she needed triple therapy but he did not have access to the third drug and it was not worth trying interferon and ribavirin alone. She also experienced delay in treatment when she was referred to King’s College Hospital because the treatment she needed was new and she did not meet the criteria for the manufacturers’ clinical trials and so she had to wait a further year for treatment.<sup>1625</sup>

There is a lesson to be learned here, that people who have been infected with such serious viruses as HIV and hepatitis value and deserve the reassurance of expertise, the absence of delay, and the ability to know that their major problems are dealt with by the co-ordinated effort of a specialist clinical team. In other words, having been infected by the National Health Service, it was and is incumbent upon that same health service to do all that could and can reasonably be done to alleviate the consequences.

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1622 Jackie Britton Transcript 3 May 2019 p56 INQY1000004

1623 Michelle Tolley Transcript 7 May 2019 pp85-86 INQY1000005

1624 Written Statement of ANON paras 26-28 WITN0074001

1625 Written Statement of Jean Smith para 15, para 17, para 30, para 33 WITN0083001



## Treatment of Hepatitis C

A common account provided to the Inquiry has been of difficulties or delays in accessing treatments for Hepatitis C, often caused by lack of resources.

Once Hepatitis C was cloned in 1988, a test for its presence could then be developed. One became available from 1989 onwards. No curative treatment was then available. However, before screening became universal in the UK (in September 1991) a research programme had already begun to evaluate the use of interferon therapy in non-A non-B Hepatitis.<sup>1626</sup> Following that, the main milestones in date order were:

- (a) In November 1994 alpha interferon was licensed for the treatment of Hepatitis C in the UK. It was thought to clear around 20 - 25% of infections.<sup>1627</sup>
- (b) Between 1994 and 2001, interferon alpha monotherapy was the only treatment licensed for use in treatment of Hepatitis C in the UK.<sup>1628</sup>
- (c) In October 2000 the National Institute for Clinical Excellence (“NICE”)<sup>1629</sup> recommended interferon alpha and ribavirin combination therapy for moderate to severe Hepatitis C; and said that “*Interferon alpha monotherapy should be*

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1626 Memo from R Anderson to Miss Webb 8 October 1990 p6 DHSC0002498\_059. Interferon is naturally produced in human cells, and its name derives from its ability to interfere with viral replication. However, as a pharmaceutical, for use in therapy, it was first licensed by the FDA in 1986. It was not at this stage licensed for therapeutic use in treating hepatitis in the UK.

1627 A Department of Health document related to the Hepatitis C lookback exercise started in 1995 recorded: “*Until recently there has been no widely accepted treatment for hepatitis C. In November 1994, a licence was granted for Interferon Alpha to be used in the treatment of chronic Hepatitis C. Interferon Alpha is the only extensively studied agent shown to be effective but results are disappointing. In approximately 50% of patients with chronic Hepatitis C who were treated with Interferon Alpha there is evidence of the virus being cleared from the body. While relapse rates are high some 20 to 25 % of patients currently being treated have a sustained response. Advances in the treatment of viral disorders are expected in the next few years that may improve response rates.*” It added, of particular interest to the Inquiry, that “*Consideration will also need to be given to ensure that those infected through NHS treatment will get access to treatment.*” Introduction of Hepatitis C lookback p5 DHSC0003533\_023. There is some reference in contemporaneous correspondence to interferon having been used for treatment “*in Specialised Centres here and around the world*” since mid 1990. Letter from Dr K Bywater to Dr Kenneth Calman 6 July 1995 DHSC0003552\_113. The effectiveness of interferon against Hepatitis C was first demonstrated by Dr Jay Hoofnagle in 1986. Hoofnagle et al *Treatment of chronic non-A non-B hepatitis with recombinant human alpha interferon* New England Journal of Medicine 1986 PRSE0001135

1628 Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 pp40-42 EXPG0000001

1629 When established as a special health authority in 1999, by means of the National Institute for Clinical Excellence (Establishment and Constitution) Order 1999, its remit extended to England and Wales. Changes to NICE’s statutory functions in 2005 applied to England only, but the Welsh Government agreed that NICE’s clinical guidance would be applied in Wales alongside guidance from the All Wales Medicines Strategy Group. Technology appraisal guidance issued by NICE has mandatory effect in Wales by virtue of a funding direction issued by the Welsh Government, requiring local health boards and trusts in Wales to make available health technologies recommended by NICE within a specified period, unless otherwise instructed by the Welsh Government. NICE guidance does not have a statutory status in Northern Ireland but formal links were established with NICE in 2006, enabling NICE’s guidance to be locally reviewed for its applicability to Northern Ireland. NICE’s remit does not extend to Scotland, which has had its own bodies undertaking similar work, including the Scottish Intercollegiate Guidelines Network and the Scottish Medicines Consortium; this work is now coordinated by Healthcare Improvement Scotland. There is, however, liaison and coordination between NICE and Healthcare Improvement Scotland.

*considered only when ribavirin is contra-indicated or not tolerated.*<sup>1630</sup> Combination therapy was thus the mainstay of treatment from now on, with interferon being part of the combination until around 2014.<sup>1631</sup>

- (d) In June 2002 pegylated interferon monotherapy was licensed in the UK. “pegylation” is the attachment of an inert molecule of polyethylene glycol to interferon, which prolongs the life (and thus the effect) of interferon in the body.<sup>1632</sup> Used as monotherapy, it was found to provide better response rates.<sup>1633</sup>
- (e) In 2011 direct-acting antivirals (“DAAs”) became available for treatment of Hepatitis C. These targeted the genes involved in the survival of Hepatitis C virus and improved sustained virological response rates, although a number of them caused additional adverse side effects. Initially DAAs – including boceprevir, telaprevir, simeprevir and sofosbuvir – were prescribed together with interferon and ribavirin which resulted in “*quite toxic combinations of treatment.*”<sup>1634</sup>
- (f) From 2014 treatment has increasingly been by a combination of sofosbuvir and other agents, without the use of interferon. Initially this was by Harvoni, given to patients with decompensated cirrhosis who were “*at risk of death or irreversible harm within 12 months*”, and/or awaiting liver transplant.<sup>1635</sup> Side effects are generally very much less and more tolerable: some people report having had none worth mentioning.<sup>1636</sup>

### Interferon: before licensing

Interferon was used in some specialist centres (on a named person basis) for some five years prior to licensing.<sup>1637</sup> Concerns about the cost of treatment with interferon were raised even before it was licensed. In a memo in 1990 regarding a pilot study of Hepatitis C screening,

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1630 NHS National Institute for Clinical Excellence *Guidance on the use of Ribavirin and Interferon Alpha for Hepatitis C* October 2000 p3 DHSC0046917\_057

1631 Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p43, p46 EXPG0000001

1632 It enabled treatment to be given with one injection to last a week, rather than a week’s treatment involving three.

1633 Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p44 EXPG0000001

1634 (Professor Graham Cooke) Hepatitis Expert Panel Transcript 26 February 2020 pp147-148 INQY1000052. Boceprevir, telaprevir, and simeprevir were taken off the market in 2018 due to their toxicity and because they only treated specific genotypes of Hepatitis C. Sofosbuvir is described by the Expert Group on Hepatitis as having “*transformed the field of hepatitis C treatment.*” Initially used with interferon and ribavirin, and causing side effects, it is now used as part of an interferon-free combination. Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 pp47-48 EXPG0000001

1635 Harvoni is the trade name for a combination of sofosbuvir and ledipasvir. Written Statement of Claire Foreman para 123 WITN3953001

1636 Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 pp47-48 EXPG0000001

1637 It was used in the UK to treat poor liver function and clear Hepatitis C prior to its licensing in 1994. Summary of case notes by Dr M Boots 10 August 1992 DHSC0006861\_210, Letter from Dr Paul Telfer to unknown DHSC0006861\_211. It was licensed for Hepatitis B in 1992. Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p39 EXPG0000001

John Canavan<sup>1638</sup> noted that additional treatment costs “*could be very substantial indeed*” if interferon were to become the established therapy for Hepatitis C carriers.<sup>1639</sup>

### Interferon: after 1994, when licensed

On 3 April 1995, the Chief Medical Officer (“CMO”) for England, Dr (now Professor Sir) Kenneth Calman, issued a “Dear Doctor” letter which enclosed guidance and procedures for the soon-to-start look-back exercise seeking to identify recipients of blood or blood components from donors now known to be carriers of Hepatitis C. It was expected that there might be 3,000 such recipients. The guidance provided that once a patient tested positive for anti-HCV they should be referred to a “*specialist with an interest in the condition for further assessment. This will usually involve a period of observation and, in most cases, a liver biopsy. Patients considered to be at risk of progressive liver disease may be offered treatment with interferon.*” The guidance went on to note that “*Effective viral therapy given early in the disease process will reduce the chance of the more serious long-term sequelae of chronic hepatitis C such as cirrhosis and the development of hepatocellular carcinoma. Interferon alpha is the only licensed therapy for chronic hepatitis C.*” The regime involved injections three times a week over a period ranging from six to eighteen months.<sup>1640</sup> Patients with significant hepatic inflammation were “*likely to be offered*” treatment whereas those with minimal disease were to be “*kept under review.*”<sup>1641</sup>

The CMO’s letter provoked questions about funding almost immediately. On 6 April 1995, Dr G Bell, Ipswich Hospital, wrote to the CMO describing how he had recently had a patient who contracted Hepatitis C from a transfusion in 1987. The hepatologist at Addenbrookes Hospital in Cambridge had advised that he be treated with interferon at Ipswich. Treatment cost £3,000 for six months: so a course could cost up to £9,000. He said “*The problem is of course, who is going to pay for the treatment?*” – was it the GP, who wanted the patient to be treated but thought funding was for the district health authority? The health authority in turn described funding as a “*grey area*” – there had been no extra provision for the cost of interferon. Dr Bell wanted advice as to how best this could be managed.<sup>1642</sup> Similarly the West Midlands Director of Public Health wrote to the Deputy CMO (“DCMO”) to say that about 300 patients infected through transfusions were expected to be identified through the Hepatitis C lookback, with potential treatment costs of £500,000, and asked “*who is going to pay.*”<sup>1643</sup>

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1638 John Canavan was in charge of the team responsible for blood policy in the Department of Health.

1639 Memo from John Canavan to Dr Smales 6 December 1990 p13 DHSC0002498\_075

1640 Usually self-administered.

1641 Letter from Dr Calman to “Dear Doctor” 3 April 1995 pp8-10 NHBT0002796\_002. Letters were also sent by the CMOs in Wales, Northern Ireland and Scotland. Letter from Welsh CMO Dr Hine to doctors 3 April 1995 BMAL0000022\_001, Letter from Dr Henrietta Campbell to “Dear Doctor” 3 April 1995 NIBS0002118, Letter from Dr Robert Kendell to “Dear Doctor” 3 April 1995 PRSE0003526

1642 Letter from Dr G Bell to Dr Calman 6 April 1995 DHSC0002556\_022

1643 Memo from Professor Rod Griffiths to Dr Jeremy Metters 10 May 1995 DHSC0003595\_015

The DCMO apologised for a late response and stated: *“patients on interferon require frequent monitoring of their blood count and biochemistry. For these reasons therefore it would be usual for hospitals rather than GPs, to prescribe Interferon. If they decide that this is what [is] required clinically, then the patient’s Health Authority [or] GP fundholder, as purchasers, will then have to consider whether or not to fund the treatment having regard to their priorities.”*<sup>1644</sup>

It seems that the funding priorities of some health authorities did not include paying for interferon therapy. On 11 July 1995 Tom Sackville, Parliamentary Under-Secretary of State for Health, said in the House of Commons that the Government was taking *“a number of measures designed to enable [those who contracted hepatitis C through NHS treatment] to receive the best possible advice and treatment”*, without giving any details of what these measures were. When problems in gaining access to alpha interferon treatment were reported to him, he undertook to look into this.<sup>1645</sup> This prompted Graham Barker of the Haemophilia Society to write to the Department of Health to say that the Haemophilia Society regarded centralised funding as being essential for matters including treatment: *“the Society believes that the provision of interferon alpha for the treatment of HCV should be centrally funded. We have examples of haemophilia centres wishing to prescribe interferon but being told that they cannot because of lack of funds. This is unacceptable. Interferon can be successful for up to 25% of those treated for this life threatening condition and should therefore be available for those who after discussion with their consultant wish to take it.”*<sup>1646</sup>

The Haemophilia Society was not a lone voice in complaining about difficulties in obtaining treatment with interferon. The issue was raised by Dr Brian Colvin, chair of the UKHCDO, at a meeting of regional haemophilia centre directors on 4 September 1995. He said he *“knew of problems in funding interferon and he thought that the Department of Health should confirm that this treatment would be funded when recommended by a physician.”*<sup>1647</sup>

Less than three weeks later, on 22 September 1995, the British Liver Trust, Haemophilia Society and Mainliners sent a letter to the Secretary of State for Health, Stephen Dorrell, saying they were particularly concerned that significant numbers of people infected with Hepatitis C, whom they as charities were working with, were not getting access to *“treatment with Interferon or other drugs”*.<sup>1648</sup>

Just a week later, the haemophilia centre directors met. Dr Frank Hill reported that it was *“an on-going battle to persuade purchasers to pay for [interferon treatment].”* It was

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1644 Letter from Dr Metters to Professor Rod Griffiths 19 June 1995 DHSC0002556\_004

1645 Hansard motion on Haemophiliacs Hepatitis C 11 July 1995 p3 WITN5290006

1646 Letter from Graham Barker to Paul Pudlo 18 July 1995 p2 DHSC0002474\_007

1647 Minutes of the UK Regional Haemophilia Centre Directors’ Committee meeting 4 September 1995 p5 HCDO0000455. It was recorded as agreed that any problems gaining funding for interferon treatment should be reported to Dr Colvin and that the issue would be raised at the next annual general meeting of the UKHCDO.

1648 Letter from Alison Rogers and others to Stephen Dorrell 25 September 1995 p1 DHSC0041441\_022. Mainliners is a charity helping people to overcome problems of addiction and blood borne viruses. Whichever the route, there is no doubt that the Department of Health must have been aware of disquiet amongst treating clinicians, patient bodies, and relevant charities about access to treatment.

proposed at the meeting by Dr Brian Colvin that Dr Andrzej Rejman, a senior medical officer at the Department of Health, be contacted if haemophilia centre directors encountered difficulties.<sup>1649</sup>

Graham Barker continued to press the point.<sup>1650</sup> On 16 November 1995 the Department of Health replied to him, to say that it did not “*hold back money centrally or allocate resources to support specific treatments for particular segments of the population*”; that funding was allocated to health authorities using a national formula; and that purchasers in local authorities were responsible for assessing the health needs of local residents, deciding which services to purchase and where to place contracts.<sup>1651</sup> In other words, there was no central funding available for treatment with interferon, and whether patients received it or not was up to their local health authority. The letter did however add that:

*“Ministers have given an undertaking to look into any problems of appropriate access to alpha interferon that may be experienced by haemophiliacs. Before decisions could be taken on any action that might need to be taken we needed more information on the nature and the extent of the problem. With this in mind the issue was raised with Directors of Haemophilia Centres at their meeting in late September. We have since received a handful of reports indicating difficulties, some of which have now been resolved.”*<sup>1652</sup>

Following further reports of interferon funding issues,<sup>1653</sup> Dr Hugh Nicholas (a senior medical officer in the Department of Health) wrote a minute on 13 December 1995 regarding the issue of the cost of interferon. This minute raised the question of whether any extra resources should be made available to fund it. He thought that the licensing of interferon, the announcement of the lookback exercise, and the Department of Health’s “*endorsement*” of the use of interferon, “*will have raised expectations among all groups infected with hepatitis C that it will be more readily available than previously when it was prescribed on a named patient basis only.*” He expressed concerns that while the Department of Health was not in

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1649 Minutes of Haemophilia Centre Directors meeting 29 September 1995 p2 HCDO0000495

1650 In letters of 19 October and 7 November 1995. Letter from Graham Barker to Paul Pudlo 19 October 1995 DHSC0041367\_047, Letter from Graham Barker to Paul Pudlo 7 November 1995 DHSC0041361\_046

1651 Letter from Paul Pudlo to Graham Barker 21 November 1995 p2 HSOC0003756\_003. Paul Pudlo headed the Department of Health blood policy team at the time.

1652 Letter from Paul Pudlo to Graham Barker 21 November 1995 p2 HSOC0003756\_003. He then wrote again on 21 November 1995 explaining that funding for interferon was the responsibility of health authorities, and informed him that the Department was still looking into the access issues he had reported. Between his letter in July 1995 and this letter, Graham Barker had reported two further cases of interferon not being provided due to funding. Letter from Graham Barker to Paul Pudlo 19 October 1995 DHSC0041367\_047

1653 On 23 November 1995, Professor Howard Thomas from Imperial College also wrote to Paul Pudlo reporting similar issues of funding for interferon treatment. The letter stated that it was “*extremely difficult*” for hospitals to provide treatment for those who the government had said would be entitled to it. He gave an example of guidance from St Mary’s hospital saying “*we should not provide interferon for patients until purchasers agreed to fund this treatment*” and asking purchasers to obtain additional funding. Other hospitals were being asked “*to make funds available from existing funds.*” Letter from Howard Thomas to Paul Pudlo 23 November 1995 p1 DHSC0003533\_088. The policy line set out in the text was adhered to in reply. Letter from Paul Pudlo to Professor Thomas 12 December 1995 DHSC0002467\_216

a position to allocate more funds to Hepatitis C treatment nor to encourage purchasers to prioritise it, *“if it is left entirely to purchasers, the allocation of resources for the treatment of hepatitis C may be very patchy across the country.”*<sup>1654</sup>

On 19 January 1996, the Department of Health wrote to the Haemophilia Society that the cases it, and the UKHCDO, had raised had been investigated, and the relevant health authorities and trusts in these instances had reported to it that interferon had now been provided. The letter added that *“It seems likely from our investigations that the difficulties you identified have resulted from teething problems associated with the relatively recent licensing of alpha interferon”*. However, it went on stoutly to defend the policy of not allocating resources for specific treatments, since this was *“based on the principle that decisions about treatment provision are best made locally, taking account of the needs of all the resident population. You will appreciate that there would be equally strong arguments in favour of prioritising money for other medical conditions which, if conceded, would undermine the principle of local decision-making.”*<sup>1655</sup>

In February 1996, the British Liver Trust released a press release noting that treatment, counselling and support services for Hepatitis C were *“inadequate”* according to a survey of liver units. It stated *“three quarters of the units were experiencing problems funding the drug Interferon, currently the only licensed treatment for HCV, and less than 15% of HCV patients were receiving Interferon.”* It went on to quote the director of the British Liver Trust, Alison Rogers: *“We are also gravely, and from the evidence justifiably, worried that a patient’s access to Interferon may be dictated by the vagaries of the NHS funding system, rather than patient need.”*<sup>1656</sup>

In April 1996, the Department of Health responded to the British Liver Trust stating that *“The majority of patients who will have been at risk of exposure to hepatitis C (i.e those treated with blood products prior to virus inactivation in 1985) have been tested for Hepatitis C and following further investigation are being treated with alpha interferon where this is considered clinically appropriate.”*<sup>1657</sup>

#### *Questions raised within the Department of Health about central funding*

Though the Department of Health had continued to hold to the principle that there would be no central funding, and that it was for local health authorities to allocate funding for those treatments they considered priorities for their resident populations, it was not maintained

1654 Minute from Dr Nicholas to Paul Pudlo 13 December 1995 p1 WITN3430028

1655 Letter from Paul Pudlo to Graham Barker 29 January 1996 p2, p4 HSOC0014304

1656 British Liver Trust *Hepatitis C numbers growing but treatment and support services remain inadequate* pp1-2 16 February 1996 DHSC0046979\_184. The British Liver Trust was reporting generally on services for those infected by Hepatitis C. The percentage receiving interferon quoted may thus relate to many people who were not infected by blood, blood products or tissue transfer.

1657 Letter from Geoffrey Podger to Alison Rogers 3 April 1996 p2 DHSC0003539\_007. The reply repeats the error the Department of Health had made in other contexts, asserting in effect that those treated with blood products after an unspecified date in 1985 had not been at risk: the truth is that in Scotland this was generally untrue until mid 1987, and in England it remained the case that commercial concentrates all placed patients at considerable risk until, in about 1989, the viral inactivation procedures of such products had improved, and self-sufficiency was much closer to being achieved.

without some questions being raised internally in the Department of Health at the same time as the complaints about difficulties with access described above occurred.

Thus, after June 1995 when the British Liver Trust had raised concerns at a meeting with Dr Jeremy Metters it was recognised that both as a consequence of past treatment with blood products and as a result of the lookback exercise there might be a substantial number of patients seeking treatment with what was an expensive drug. Hepatitis following intravenous drug use was increasingly common, and the Department of Health saw no reason why treatment should not be given to those infected in that way on an equal footing to those who had received infected blood, tissue or blood products. Thus, an internal note of 2 October 1995 said that the issues raised by this needed to be discussed. There were “*general policy questions*” including “*the tension between (a) the need for a central initiative to deal with a potentially significant public health problem and (b) the aim of leaving the NHS to determine its own priorities based on assessment of local needs*” and there was a need to “*confirm whether we maintain the line in response to requests for departmental action on additional resources, ie: that purchasers should take decisions based on local priorities*”.<sup>1658</sup>

The principle applied did not change. When in May 1996 Dr Metters checked what had been said officially about treatment, he was told that the commitment given was “*to provide treatment where appropriate (or necessary)*” and that “*There has been no firm commitment to provide treatment – as distinct from referral for specialist opinion – in every case.*”<sup>1659</sup> The only commitment (as such) was a ministerial one “*to investigate allegations of problems of access to alpha interferon.*”<sup>1660</sup>

#### *Whether to issue Guidance, which might skew local funding allocations*

The Department of Health continued to mull over the question of whether it should issue specific guidelines to purchasers about funding interferon treatment throughout 1996. It could have used its powers to issue guidance to ensure that, in specified circumstances, a health authority understood that it should give priority to it.

A paper was prepared for a meeting of the NHS Executive to be held on 13/14 June 1996. This paper covered a range of issues raised by Hepatitis C infections. It included the following:

*“The cost of treatment with alpha interferon (£2-5,000/patient) is already placing a considerable burden on purchasers and the pressure to prescribe Alpha Interferon widely is growing. Alpha Interferon is, however, of limited overall clinical and cost effectiveness and its widespread use poses a dilemma. To deny any individual patient, however infected, a trial of a drug that may prevent their*

1658 Memo from Claire Phillips to Edmund Waterhouse 2 October 1995 p5 DHSC0003552\_018

1659 Memo from Ann Towner to Dr Metters 22 May 1996 p2 DHSC0004056\_009. Extracts were set out from various official sources which amply supported this summary. Commitment on treatment for those infected with Hepatitis C through blood/blood products DHSC0004056\_010

1660 Note of meeting with John Marshall MP to discuss compensation for haemophiliacs with Hepatitis C 24 April 1996 p5 DHSC0041255\_074. The commitment related to those whose treatment under the NHS had led to their infection.

*developing serious liver damage or even cancer is contentious, and may lay Ministers open to criticism (or even litigation). Conversely, to encourage people to seek treatment at a time when they are asymptomatic and may remain so for decades, during which time more effective treatments are almost certain to be developed, is equally questionable (and costly – potentially up to £51m additional cost in 1997/8). **There is, therefore, also a case for issuing guidance to the NHS on the management of HCV.***<sup>1661</sup>

When the NHS Executive Board discussed the paper, it agreed that measures needed to be taken in the interests of public health, but reached no conclusion as to guidance, or what should be funded: further policy development “*would be affected by the views of professionals ... research findings and other information*”.<sup>1662</sup>

There were a number of internal discussions in the Department of Health about issuing guidance, and a range of different views. The CMO (who had by now seen the paper) and colleagues from the Department of Health met on 16 July 1996. Dr Graham Winyard (who had drafted the paper in the first place and was Medical Director for the NHS Executive) told them that the NHS Executive Board had not yet come to a firm view, and a cautious approach was necessary.<sup>1663</sup> In relation to a meeting the following day one of the attendees recorded: “*This morning’s meeting seemed to start from the presumption that the Department ... would be developing, as a matter of some urgency, purchasing and clinical advice on the management of HCV and Alpha Interferon ... I explained that the [NHS Executive] Board had not yet come to a firm view on handling, so a cautious approach seemed necessary*”.<sup>1664</sup>

Dr Winyard’s advice was thus repeated, though there was thought to be:

*“a strong case, on public health grounds, for at least developing clinical guidelines on the management of HCV, including the use of Alpha Interferon. However, in order to take account of last week’s Board views, and to arrange for guidelines to be developed which are robust and likely to be commendable ... they expect such guidelines to be developed over a fairly slow timescale – taking up to about a year. They will seek input from professional and patient interest groups in developing the guidelines.”*<sup>1665</sup>

By November 1996, however, officials had made the decision not to recommend issuing purchasing guidelines. The reason was the likely impact their issue would have on health authorities.<sup>1666</sup>

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1661 Paper by Dr Graham Winyard on Hepatitis C p2 DHSC0006348\_083. Emphasis in original.

1662 Minutes and action notes of NHS Executive Board meeting 13/14 June 1996 p2 DHSC0044009\_023. After this, the paper went to the CMO. Briefing for UK CMOs Meeting: Hepatitis C 24 June 1996 p2 DHSC0006348\_081

1663 Memo from Donna Sidonio to Charles Dobson 17 July 1996 p1 DHSC0004056\_005

1664 Memo from Donna Sidonio to Charles Dobson 17 July 1996 p1 DHSC0004056\_005

1665 Memo from Donna Sidonio to Charles Dobson 17 July 1996 p1 DHSC0004056\_005

1666 Inferentially, the cost commitment this would create. Memo from Clare Phillips to Drs Metters and Winyard 19 November 1996 DHSC0004203\_024



On 23 December 1996, a final submission (agreed by the NHS Executive Board) was sent to the office of the Parliamentary Under-Secretary of State for Health, John Horam, highlighting the increased expectations of Hepatitis C treatment, particularly for those infected through receiving blood transfusions and blood products, following the lookback exercise. The submission noted that *“Specific commitments have been given about the provision of treatment in respect of haemophiliacs”* and also stated that *“Purchasers in some areas have made it clear that they are not willing to pay for treatment of Alpha Interferon”*.<sup>1667</sup> The recommendation was that the Department of Health did not issue any purchasing guidance as it may be read as giving *“an implicit signal to purchasers about the priority to be attached to a particular condition or treatment”* which purchasers would not welcome, *“but factual information would be helpful to purchasers and professionals working in the field.”* It was noted that treatment with interferon was a matter of clinical judgement and decisions around funding were to be made by local health authorities.<sup>1668</sup>

John Horam sent this to the Secretary of State, Stephen Dorrell, noting *“The reason for concern is the potential timebomb of an estimated 150,000 to 300,000 people who may be infected.”* He wrote that he was broadly supportive of the recommendations, including not to issue purchasing guidance *“but to make clear that decisions should be made locally (no blanket bans), supported by clinical guidance which the profession are developing.”* He added that *“some awkward questions will remain”* which included that:

*“there are two main groups of patients; haemophiliacs and others who were infected as a result of (NHS) treatment, and injecting drug misusers who have shared equipment. Morally, one might distinguish between these two groups (especially given the resource implications of treatment), but providing different treatment to people depending on how they were infected would be controversial.”*<sup>1669</sup>

On 12 February 1997, Stephen Dorrell and John Horam discussed the approach to Hepatitis C: *“on clinical guidance, Secretary of State noted the plans to promulgate guidance produced by the [Royal College of Physicians] ... He suggested that GPs should have a greater role in identifying, diagnosing, treating and referring HCV as appropriate, and that GP involvement should be secured ... The most effective way to do this should be through a letter from CMO to the [Royal College of General Practitioners].”*<sup>1670</sup> In his written statement, Professor Sir Kenneth Calman notes that *“The direction of policy seems then to have been set and did not change throughout 1997, including after the General Election of May 1997 and subsequent change of government.”*<sup>1671</sup>

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1667 Submission on Hepatitis C (HCV): The Current Position 23 December 1996 p4, p7 DHSC0004203\_013. The annex to the submission noted *“Ministers have given commitments to help, including investigating alleged problems of access to Alpha Interferon for [haemophiliacs]. So far the few cases identified have been readily resolved.”*

1668 Submission on Hepatitis C (HCV): The Current Position 23 December 1996 p6 DHSC0004203\_013

1669 Memo from John Horam to to the Secretary of State 23 January 1997 p1 WITN5294018

1670 Note of a meeting on Hepatitis C handling 12 February 1997 p1 DHSC0004203\_004. Underlining in original.

1671 Written Statement of Professor Sir Kenneth Calman para 62.19 WITN3430001

Until the end of 1997, therefore, the issuing of clinical guidance was left in the hands of the profession, rather than being the subject of a letter from the CMO, or formal government guidance.

On 13 November 1997, a policy submission was sent to the offices of the CMO and the Ministers of State, Tessa Jowell (later Baroness Jowell) and Baroness Margaret Jay. It noted that some health authorities were refusing to fund alpha interferon due to its cost and belief it was of limited clinical effectiveness.<sup>1672</sup> A consequence of this was that *“In some areas, this continues to deter specialists from prescribing alpha interferon or leads to long delays in treatment whilst negotiations ensue.”* Having also noted the *“specific commitments”* made to provide testing and, where required, treatment for those infected by NHS treatment,<sup>1673</sup> the submission went on to record that the department was supporting the medical profession financially and administratively in the production of clinical guidelines. If favourably appraised, then the NHS Executive would commend the guidelines to the NHS early in 1998. It concluded that *“The ambiguity about the circumstances in which it is appropriate to use alpha interferon should be resolved through the development and approval of clinical guidelines ... these guidelines could then form the basis for encouraging a more consistent approach across the NHS.”*<sup>1674</sup> However, the submission did not go as far as saying that what was recommended by the guidelines should be funded by the health authority – the recommendation was that *“if asked about the availability of treatment, we reiterate that the management of patients with HCV is a matter for clinical judgement and there should be no blanket bans on alpha interferon treatment.”*<sup>1675</sup> The submission recommended continuity and the Inquiry has seen no record that the Ministers disagreed.

By the end of December 1999, two years on, despite the forecast about an earlier date for appraising clinical guidelines, no clinical or purchasing guidelines had yet been introduced relating to the treatment of Hepatitis C.<sup>1676</sup> The position of the Department of Health was still that *“Funding for treatment is a matter for the local health authority.”*<sup>1677</sup>

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1672 Cure rates for interferon were much lower than later treatments. See Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p43 EXPG0000001

1673 The submission explained these commitments as:

a) *For people identified through the Hepatitis C lookback: “Previous Ministers gave assurances that these patients would be tested and, if appropriate, treated.”*

b) *“haemophiliacs were promised that any alleged problem of access to the treatment would be investigated”.*

The words *“if appropriate”* give considerable leeway: it falls short of a guarantee of treatment and does not specify who was to decide if treatment was appropriate or not. Memo from Claire Phillips to Dr Shepherd and others 13 November 1997 pp2-3 WITN3430176

1674 This shows that the approach was not a consistent one but varied from health authority to health authority. Memo from Claire Phillips to Dr Shepherd and others 13 November 1997 p6 WITN3430176

1675 Memo from Claire Phillips to Dr Shepherd and others 13 November 1997 pp2-3, p6 WITN3430176

1676 The clinical guidelines were still under development. There was a workshop at the Royal College of Physicians in December 1997 and the guidelines were presented to the London meeting of the British Association for the Study of the Liver in 1999 *“where consensus was achieved on some of the more controversial issues.”* Royal College of Physicians and British Society of Gastroenterology *Clinical guidelines on the management of hepatitis C* Gut July 2001 p1 RLIT0002368

1677 Memo from Dr Vicki King to Katherine Staton 24 December 1999 p1 DHSC0038649\_014

In summary, in the period up to 2000 from the licensing of interferon in 1994 there were repeated issues with an inability to access interferon treatment for Hepatitis C under the NHS in England. Provision to access was not consistent across the country. Measures that could have helped to address problems over access to treatment, such as clinical guidelines, purchasing guidelines and centralised funding, were still not in place after five years. In his written statement to the Inquiry, Professor Sir Kenneth Calman noted that the issues involved “*were common across the NHS when new drugs or treatments emerged.*”<sup>1678</sup> Dr Rejman noted in his statement that “*it appears that DH [Department of Health] was encouraging the use of Interferon, where it was appropriate, but accepting that the final decision rested with the purchasers.*”<sup>1679</sup>

Meanwhile in Scotland, a working party of the Royal College of Physicians of Edinburgh produced a report on Hepatitis C in February 1996 and noted:

*“There is currently no general agreement as to who should meet the drugs costs, general practitioner or hospital. There is a growing tendency in Scottish regions to set up special drug lists and ‘prescribing interface’ meetings to establish local policies. In general, the clinicians carrying the responsibility for prescribing (and its safety) would be expected to be the ‘cost bearer’. In the smaller regions of Scotland the additional numbers generated by a lookback survey are relatively modest and may be largely absorbable into existing budgets. In the west of Scotland, in particular, the additional costs are likely to be substantial.”*<sup>1680</sup>

At an SNBTS medical and scientific committee meeting on 11 September 1996, it was reported that there was “*considerable demand*” for interferon in Scotland “*but, as yet, no ‘ring fenced’ money.*”<sup>1681</sup> At the next meeting on 17 December 1996, Dr (later Professor) Aileen Keel “*advised that ‘ring fenced’ funding for interferon treatment would not materialise.*”<sup>1682</sup>

## Treatment of Hepatitis C 2000 onwards

In April 1999, the National Institute for Clinical Excellence (“NICE”) was established to provide clinical guidelines for England and Wales and reduce postcode prescribing.<sup>1683</sup> In May 1999 ribavirin was licensed for distribution in the UK<sup>1684</sup> and in October 2000 NICE

1678 Written Statement of Professor Sir Kenneth Calman para 62.24 WITN3430001

1679 Written Statement of Dr Andrzej Rejman para 120.6 WITN4486040

1680 Royal College of Physicians of Edinburgh *Hepatitis C* February 1996 p10 SBTS0003039\_001

1681 Minutes of SNBTS Medical and Scientific Committee meeting 11 September 1996 p2 SBTS0003666\_124

1682 Minutes of SNBTS Medical and Scientific Committee meeting 17 December 1996 p2 SBTS0003978\_037. Emphasis in original. Dr Keel was then a senior medical officer in the Scottish Office, a status she held 1992-1998, then becoming a principal medical officer 1998-1999, and DCMO 1999-2014.

1683 It later joined with the Health Development Agency to become the National Institute for Health and Clinical Excellence on 1 April 2005 and became the National Institute for Health and Care Excellence on 1 April 2013 following the Health and Social Care Act 2012. It has retained its original abbreviation.

1684 Parliamentary written answer on Hepatitis C 13 October 1999 p2 DHSC0032341\_053. Ribavirin had been available on a named patient basis prior to licensing. Briefing on Hepatitis C Payment Scheme p11 24 May 1999 DHSC0006176\_072

guidelines for the use of interferon and ribavirin were introduced.<sup>1685</sup> While interferon had low cure rates, the addition of ribavirin increased cure rates of Hepatitis C “*quite significantly*”.<sup>1686</sup> The NICE guidelines recommended that combination therapy be used to treat moderate to severe Hepatitis C.<sup>1687</sup>

On 5 December 2001, the Department of Health introduced a statutory obligation for the NHS to provide funding for NICE-recommended medicines and treatments from three months following approval.<sup>1688</sup> This took effect in January 2002.<sup>1689</sup> Pegylated interferon was licensed as a combination therapy with ribavirin, and then recommended by NICE on 28 January 2004.<sup>1690</sup> Thus from that date, funding for its provision was mandated in England and Wales.<sup>1691</sup>

### Hepatitis C action plans

Between 2002 and 2010, all four nations of the United Kingdom developed action plans aiming to improve treatment services for Hepatitis C.

#### *England*

In 2002, the CMO of England, Liam Donaldson, published *Getting Ahead of the Curve*, a strategy for infectious diseases. The strategy identified the high prevalence of Hepatitis C in England and announced a specific strategy to bring together actions to improve Hepatitis C awareness and treatment.<sup>1692</sup> In August 2002, the *Hepatitis C Strategy for England* set out “*proposals to improve the effectiveness of prevention, diagnosis and treatment services for hepatitis C.*”<sup>1693</sup> The *Hepatitis C Action Plan* set out a framework for how to implement the strategy. It identified that treatment services varied across different parts of the country and detailed a need for high-quality health services for the assessment and treatment of those with Hepatitis C.<sup>1694</sup>

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1685 NHS National Institute for Clinical Excellence *Guidance on the use of Ribavirin and Interferon Alpha for Hepatitis C* October 2000 DHSC0046917\_057

1686 (Professor Graham Cooke) Hepatitis Expert Panel Transcript 26 February 2020 p127 INQY1000052. Figure 15.13b in the expert report on hepatitis to the Inquiry shows the improvements in rates of sustained virological response over time. Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p43 EXPG0000001

1687 NHS National Institute for Clinical Excellence *Guidance on the use of Ribavirin and Interferon Alpha for Hepatitis C* October 2000 p3 DHSC0046917\_057

1688 Briefing on parliamentary question on Hepatitis C 17 February 2003 p55 WITN4680016

1689 Department of Health *Hepatitis C Strategy for England* August 2002 p39 WITN6942004

1690 National Institute for Health and Care Excellence *Interferon alfa (pegylated and non-pegylated) and ribavirin for the treatment of chronic hepatitis C* 28 January 2004 RLIT0002329

1691 See footnote 1629 for the position in Wales from 2005.

1692 Department of Health *Getting Ahead of the Curve: A strategy for combating infectious diseases (including other aspects of health protection)* January 2002 pp73-76 RLIT0001745

1693 Department of Health *Hepatitis C Strategy for England* August 2002 p7 WITN6942004

1694 Department of Health *Hepatitis C Action Plan for England* July 2004 p7, p12, p17 SAFT0000066

## Scotland

Scotland introduced a Hepatitis C Action Plan in 2006 which identified that there was “a serious problem in many areas of Scotland with the accessibility of treatment services”, and a “need for a substantial new funding to expand Hepatitis C treatment”. To decide quite how much funding was needed, and how and where it should be provided, the Scottish Executive was to commission a study to assess the nature and level of the need for treatment-related funding in each NHS board area in Scotland.<sup>1695</sup>

The second phase of the Hepatitis C Action Plan was introduced in 2008, which published the results of data gathering, showing that an “insufficient” number of people were being diagnosed and receiving antiviral treatment and that there were inequalities across Scotland in treatment. The 2008 Hepatitis C Action Plan indicated a major Government investment of £43.2 million over three years to tackle Hepatitis C better. One of the actions was for there to be an increase in the number of persons receiving antiviral therapy from 450 a year to 2,000 a year from 2011.<sup>1696</sup>

## Northern Ireland

The *Action Plan for the Prevention, Treatment and Control of Hepatitis C in Northern Ireland* was published in January 2007 and included action to ensure that NICE guidance was adhered to: “HSS [Health and Social Services] Boards and Trusts are required to take account of DHSSPS [Department of Health, Social Services and Public Safety]-endorsed NICE guidance on the treatment of people with chronic hepatitis C, within clinical priorities and available resources.”<sup>1697</sup>

## Wales

The *Blood Borne Viral Hepatitis Action Plan* in Wales was published in August 2007. This identified the low level of people receiving treatment for Hepatitis C, and the need to improve treatment considering a cost effective treatment was available and NICE guidelines supported the use of combination therapy treatment. It aimed to improve the provision of treatment and support to infected individuals. The action required for change was to implement “High quality and adequately resourced hepatitis treatment” as well as to “Monitor implementation of combination therapy for the treatment of HCV and HBV infection across

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1695 NHS Scotland *Hepatitis C Action Plan for Scotland Phase 1: September 2006 to August 2008* September 2006 pp18-20 PRSE0004153

1696 The Scottish Government *Hepatitis C Action Plan for Scotland Phase II: May 2008 – March 2011* May 2008 p9, p11, p13 WITN7249007. By 2017 Scotland was cited by the World Health Organization as a “model country” in terms of response to the Hepatitis C challenge. Health Protection Scotland *The Scottish Government Hepatitis C Treatment and Therapies Group Report* February 2017 p6 RLIT0002303

1697 Department of Health, Social Services and Public Safety *Action Plan for the Prevention, Management and Control of Hepatitis C in Northern Ireland* January 2007 p5 WITN5570015. See also: Strategic Framework and Action Plan for the Prevention and Control of Hepatitis C in Northern Ireland 2004-2007 WITN5570014

*Wales in line with NICE technology appraisals. Ensure eligibility criteria and consistently applied in all areas of Wales. Identify and address shortfalls in services*.<sup>1698</sup>

In 2006, an article on the variation in Hepatitis C services in the UK was published, based on a survey conducted in 2002 which found that 72% of consultants who responded identified funding as a barrier to treatment. The survey found that the majority of patients were not receiving antiviral treatment, in contrast with practice in Europe.<sup>1699</sup>

## 2014 onward

Interferon-free treatments became available from 2014. These were a combination of sofosbuvir and other agents which “*ensured high treatment rates were achievable*” without the additional use of interferon.<sup>1700</sup> However the costs of these treatments were high and caps on the number of people who could receive treatment in each area limited access.

In England, early access programmes were implemented for DAAs prior to the implementation of NICE guidelines.<sup>1701</sup> The first early access programme began in April 2014 and provided treatment with sofosbuvir to patients with decompensated cirrhosis, “*at risk of death or irreversible harm within 12 months*” with either decompensated cirrhosis, other life-threatening complications and/or awaiting liver transplantation.<sup>1702</sup> Access for “*critically urgent*” patients was considered on an individual basis by NHS England clinical experts.<sup>1703</sup>

2015 was a year in which it is now clear that funding issues had an impact on access to treatment. In February NICE issued guidelines for treatment with sofosbuvir. It would normally be expected that this would lead to compliance within three months. However, NHS England requested that their implementation be delayed until 31 July that year. Four reasons were put forward for the delay, including: “*A substantial demand for treatment with sofosbuvir, which it anticipates will increase further, because patients who have not sought active treatment in the past will come forward, and which will be increased further by new*

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1698 National Public Health Service for Wales *Blood borne viral hepatitis action plan for Wales* 1 August 2007 p12, p23, p25 RLIT0002304

1699 Parkes et al *Variation in Hepatitis C services may lead to inequity of health-care provision: a survey of the organisation and delivery of services in the United Kingdom* BMC Public Health 10 January 2006 p5, p7 RLIT0002367. The survey was sent to 344 consultant hepatologists, infectious disease consultants, gastroenterologists and genito-urinary medicine consultants and had a 70% response rate.

1700 Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p48 EXPG0000001

1701 In her written statement, Claire Foreman sets out the relationship between the NHS, NHS England and NICE. She notes that NHS England “*funds approved drug treatments and therapies*”. Treatments are recommended for licence by the Medicines and Healthcare products Regulatory Agency and the Department of Health and Social Care formally requests NICE to assess the treatments. “*If NICE issues a recommendation ... [integrated are systems], NHSE [NHS England] and (with respect to their public health functions), local authorities, are required to comply with the recommendations. This includes making funding and/or services available to enable access generally within 3 months of the publication of recommendations.*” Written Statement of Claire Foreman paras 26-27, para 123 WITN3953001. Claire Foreman was head of acute programmes within the specialised commissioning directorate of NHS England before becoming director of medicines policy and strategy.

1702 Written Statement of Claire Foreman paras 120-123 WITN3953001. This was 18 months before recommendations were published for sofosbuvir/ledipasvir (Harvoni).

1703 Written Statement of Claire Foreman para 123 WITN3953001

*patients identified through public awareness campaigns and screening of high-risk groups, which have either been initiated or which are planned.*<sup>1704</sup> The extension was granted on the basis that the treatment could not be “*appropriately administered*” until certain health service infrastructures were in place.<sup>1705</sup>

Before this was implemented, the Penrose Inquiry published its final report. This led to discussion within the Department of Health.

On 25 March 2015, the same day the Penrose Report was published, Prime Minister David Cameron announced in Parliament that the Government would provide “*up to £25 million in 2015-16 to support any transitional arrangements to a better payments system.*”<sup>1706</sup> Subsequently, Jeremy Hunt, as the Secretary of State for Health, wrote to David Cameron, setting out three options for support to replace the existing Alliance House Organisations. In the course of discussing these, Jeremy Hunt noted that:

*“Additionally a new Hepatitis C treatment which can clear the infection has recently become available. The NHS has introduced an accelerated treatment programme for those with greatest clinical need. Only around 800 of the infected blood cohort are eligible, leaving 2,500 with no early access to the new treatment. Under this option all 2,500 would get accelerated access. This would be funded by us paying for private treatment as we would not be able to use NHS funds to allow them to jump the queue ahead of other NHS patients in greater clinical need. There is a risk in this option that it would create a precedent for the DH to be lobbied for funding treatments that NHS England does not currently provide but I believe this is manageable given the exceptional historic circumstances.”*

Expenditure on access in this way was a substantial part of his second option for the replacement of the Alliance House Organisations, though that option overall was said to be more costly than the Department of Health’s current budget would permit. His third option however suggested that “*with the agreement of yourself and the Chancellor I would be prepared to absorb an additional £100m pressure in the DH budget to fund accelerated access to the new Hep C treatment for all those in the early stage of the disease. This would come from DH funds and would not be funded through the NHS England mandate – indeed*

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1704 The other three reasons were:

- *“The need to complete the work of the ‘task and finish’ service redesign group ...*
- *The need to establish a hepatitis C network, which will involve setting up a series of centres with the staff and the other resources and systems necessary to provide a multidisciplinary team approach to care.*
- *The establishment of a national database and dashboard to monitor and support individual care.”*

National Institute for Health and Care Excellence *Sofosbuvir for treating chronic hepatitis C* 25 February 2015 p88 WITN3953024, The Guardian *Hepatitis C drug delayed by NHS due to high cost* 16 January 2015 p1 RLIT0002300

1705 National Institute for Health and Care Excellence *Sofosbuvir for treating chronic hepatitis C* 25 February 2015 p92 WITN3953024. The delay was granted under section 7(5a) of the National Institute for Health and Care Excellence (Constitution and Functions) and the Health and Social Care Information Centre (Functions) Regulations 2013. It is Section 7(6) which requires NHS England and local authorities to comply with NICE recommendations within three months of publication.

1706 Hansard oral answer on Contaminated Blood 25 March 2015 p1 CELC0000002\_030

would be most likely to be provided privately. This additional £100m would be on top of the ongoing costs of the payment schemes.”<sup>1707</sup>

Though in both these two options a need for using money to facilitate early access for patients who had been infected in the course of their treatment was put forward by Jeremy Hunt, the response to him was that the Prime Minister “*didn’t indicate any interest in pursuing the option of accelerated HepC treatment so we can discount this option for now.*” The Prime Minister preferred to “*effectively ‘level up’ the payments so that there is equity between those with Hep C and those with HIV.*”<sup>1708</sup>

The reference in Jeremy Hunt’s letter of 30 June 2015 to the NHS having introduced an accelerated treatment programme for those with greatest clinical need was a reference to an early access programme which was introduced earlier that month.<sup>1709</sup> This gave patients with decompensated cirrhosis access to sofosbuvir ahead of it being available in August 2015, as well as other new DAAs.<sup>1710</sup>

Around the same time, in 2015, Scotland introduced a policy of prioritising antiviral therapy, in terms of timing only, for those with moderate to severe liver disease. This was introduced in order to attempt to reduce the incidence of Hepatitis-C-related liver failure in Scotland with the newer effective but expensive DAA therapies. The policy of prioritisation ended in April 2018.<sup>1711</sup>

Following the implementation of NICE guidelines, funding for DAAs was provided through operational delivery networks across England. Each one was provided with a proportion of the budget for Hepatitis C treatment based on the estimated treatment figures for the area covered and the local prevalence of Hepatitis C.<sup>1712</sup> There were some examples of

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1707 Letter from Jeremy Hunt to David Cameron 30 June 2015 p3 CABO0000163\_003

1708 Email chain between Heulwen Philpot, Helen Shirley-Quirk and others 6 July 2015 p2 WITN3499021. Jeremy Hunt described this as “*a political judgement. He may well have been right. I took a slightly different judgement because, within the 125 million, I wanted to prioritise treatment and make sure that everyone who had hep C got treatment really quickly ... I understand why he made the judgement he made.*” Jeremy Hunt Transcript 27 July 2022 p95 INQY1000235

1709 NHS England *Clinical Commissioning Policy Statement: Treatment of chronic Hepatitis C in patients with cirrhosis* June 2015 p10 WITN3953023

1710 Sofosbuvir/ledipasvir, sofosbuvir/daclatasvir, ombitasvir-paritaprevir-ritonavir. NHS England *Clinical Commissioning Policy Statement: Treatment of chronic Hepatitis C in patients with cirrhosis* June 2015 pp7-9 WITN3953023

1711 Health Protection Scotland *Scotland’s Hepatitis C Action Plan: Achievements of the First Decade and Proposals for a Scottish Government Strategy (2019) for the Elimination of both Infection and Disease* July 2019 pp16-17 WITN4062002. Giving priority to those with moderate or severe liver disease was effective, because interferon-based therapy was more effective in those with mild to moderate disease than it was in those with more severe disease, whereas sofosbuvir was effective in both. Giving priority for receipt of DAAs to the more severe categories meant that although some mildly to moderately affected patients did receive them, the balance of those receiving them swung such that whereas 40% of those treated had previously been moderately to severely affected it was now 60%; and the overall impact of DAAs was maximised, with a substantial benefit in the proportion of those who cleared the virus. See also the evidence of Professor John Dillon, clinical lead for Hepatitis C in NHS Tayside. Professor John Dillon Transcript 17 November 2022 pp38-47 INQY1000264

1712 Written Statement of Claire Foreman paras 137-139 WITN3953001. Established in 2013, operational delivery networks coordinate specialist services over different areas in England. NHS Commissioning Board *Developing Operational Delivery Networks: The Way Forward* December 2012 RLIT0002301



patients not receiving treatment due to the resultant limit on allocations. Though accepting that was the case, Claire Foreman, on behalf of NHS England, explained that nonetheless *“the case and treatment rates were roughly in line with those set out in the approach that [NHS England] took”*.<sup>1713</sup>

The experience of patients, as described to the Inquiry, is that there have been difficulties with access to treatment. Samantha May describes the allocations as initially *“small compared to those in need of treatment.”* She stated that the Hepatitis C Trust often *“heard from our callers that their consultants told them they were ‘lucky’ to receive this new treatment and they should be ‘grateful’ due to the initial high cost.”*<sup>1714</sup> Robert James, a campaigner involved in the field of patient involvement and treatment activism, noted that the *“rationing of this treatment by NHS England, despite approval from NICE that the treatments met the cost-effective criteria ... delayed the availability of effective hepatitis C treatment to many people with haemophilia in England.”*<sup>1715</sup>

One man said that when Harvoni became available he knew it would eventually be approved by NICE but: *“for me, in my condition every day that passed was vital. Even though I ran the risk of forking out huge sums of money only for it to then become available on the NHS soon after, I decided to fund the treatment myself.”* He arranged to borrow £60,000 and explains: *“I couldn’t bear the pain of not knowing how long I would have to wait. It felt like I was playing Russian roulette with my life.”* Ultimately the treatment was funded by the NHS.<sup>1716</sup> David Gort self-funded his Harvoni treatment because it was unclear when the NHS funded treatment would be provided. He used the majority of his second stage Skipton Fund payment to obtain the treatment.<sup>1717</sup> Kenneth Gray said that he and his late wife would have done the same if they had known it was possible: *“I would have moved heaven and earth with no hesitation in order to secure further precious time with my Sandra”*.<sup>1718</sup>

The situation in Wales appears to have been similar before the allocation of funding for DAAs. Julie Morgan, who campaigned on behalf of haemophilia patients in Parliament and then the Senedd, describes access to Hepatitis C treatment in Wales as having been a *“postcode lottery”* where availability and quality differed across parts of Wales but she remembered the announcement in September 2015 of £13.8 million for interferon-free treatment as a turning point.<sup>1719</sup> The approach to DAAs was different from that in England. There was no central

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1713 Written Statement of Claire Foreman paras 145-146 WITN3953001. See also the evidence of Professor Graham Foster about the phases of NHS England’s Hepatitis C elimination programme, for which he was national clinical chair. Written Statement of Professor Graham Foster paras 7-11 WITN3042004, Professor Graham Foster Transcript 17 November 2022 pp6-9 INQY1000264

1714 Samantha May is the helpline information and support service manager for the Hepatitis C Trust. Written Statement of Samantha May para 141, para 146 WITN0912001

1715 Written Statement of Robert James para 47 WITN1004001

1716 Written Statement of ANON paras 22-25 WITN4211001

1717 Written Statement of David Gort paras 26-29 WITN1244001

1718 Written Statement of Kenneth Gray para 27 WITN0491003

1719 Written Statement of Julie Morgan p5 WITN2438001. She also described how the NHS England delay to implementation of the 2015 NICE guidelines had a *“knock-on effect”* for patients in Wales since their treatment was also delayed. Julie Morgan was a Member of Parliament (1997-2010) and subsequently a Member of the Senedd.

process of capping the numbers of patients who could be treated with DAAs, though for the first two years treatment was prioritised based on clinical need.<sup>1720</sup>

Caroline Leonard, on behalf of the Belfast Health and Social Care Trust, acknowledged that patients had had to wait, both for a hepatology referral and for treatment:

*“Prior to November 2017, patients with HCV were offered a routine appointment and waited along with all other hepatology referrals for a first appointment ... In November 2017, following agreement with the [Health and Social Care Board], [the Belfast Health and Social Care Trust] commenced a series of waiting list initiative clinics dedicated to HCV patients ... by Autumn 2019, the waiting time for someone with HCV to be seen at clinic was reduced to around 8 weeks with a plan to start treatment within 3-4 weeks of assessment if the patient meets the NICE eligibility criteria for treatment.”*<sup>1721</sup>

There is a tension between different principles here. One view is that anyone who has been harmed by their treatment should be regarded as a priority for the further treatment that will help to limit the harm, whilst recognising that this means that people who have not been harmed in the same way, but are in greater clinical need, have to wait. The alternative view is that treatment should be strictly according to clinical need; and that the fact that one cohort has been harmed should give its members no preference. These intersect with another principle. Where some funding is available it is unconscionable for everyone who might take advantage of it to have to wait until it is available for all. What there is should be used at least for some (in effect, this is “rationing”). Rationing implies that there is a fair basis on which some get a little, rather than all getting everything all at once. If treatment is funding-dependent, and funds for it are limited, that means that there has to be a defensible basis for distribution. It may be that treatment is being trialled. A trial will prioritise some for receipt. It can be by region, but the idea of a “postcode lottery” is uncomfortable, since there is little fairness evident about that. There was, in the circumstances described in this Report, a defensible line that could have been drawn, to favour the smaller group who had suffered because of the treatment they had received, earlier than it was.

There had already been an acceptance that for some purposes a line should be drawn around people with haemophilia with Hepatitis C infection: thus an internal submission at the end of 1996 recorded that *“Specific commitments have been given about the provision*

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1720 Professor Chris Jones, DCMO, told the Inquiry: *“The Welsh Government allocated additional resources to health boards for the new antiviral medications in 2015/16. Funding was allocated in line with anticipated health board treatment demand and there was no cap put on the number of patients that could be treated within any health board.”* Written Statement of Professor Chris Jones para 11 WITN4065001. Dr Brendan Healy, blood-borne virus clinical lead for Wales, told the Inquiry that for the first two years treatment with DAAs was prioritised based on clinical need. Dr Brendan Healy Transcript 17 November 2022 p69 INQY1000264

1721 Written Statement of Caroline Leonard para 7.2 WITN3449023. Caroline Leonard was director of surgery and specialist services at the Belfast Health and Social Care Trust. In Northern Ireland, the limited capacity of the hepatology service, rather than funding constraints, was the barrier to accessing these therapies.

*of treatment in respect of haemophiliacs*”;<sup>1722</sup> and in 1997 John Horam had suggested that “*morally*” a distinction might be drawn in favour of those who had been infected by NHS treatment, though he recognised that doing this might be controversial.<sup>1723</sup> In a similar vein, when Jeremy Hunt put forward his three options for replacing the Alliance House Organisations, one option he proposed was that the 2,500 people within “*the infected blood cohort*” who had not thus far had accelerated access to sofosbuvir-linked treatments should be funded to receive it. His answer to the question of principle whether the NHS should prefer a group on any criterion other than clinical need was that the NHS itself would not provide it – but the Government would, by funding private treatment. His argument on the issues of fairness for singling out people infected through blood or blood products preferentially was “*the exceptional historic circumstances*.”<sup>1724</sup>

In short, the principle that a line should be drawn around this group, and the group prioritised, was accepted (at least in effect by the Secretary of State for Health, Jeremy Hunt, if not by Government as a whole). It would have been a fair line to draw.

At the time that these funding questions arose more acutely, sofosbuvir was becoming more generally available without the use of interferon. But it was also at this time that it was becoming better appreciated that most people who had been infected with hepatitis through their treatment should not have been. The basis which had been maintained for years that people who had been infected in this way were in no different a position to anyone else who had suffered unexpected consequences after treatment, where the treatment itself had not been negligent, was being seriously questioned. Facts revealed by the Archer and Penrose inquiries raised significant doubts.

However it was not yet recognised that wrongs were done at individual, collective and systemic levels to people who had received blood or blood products from the NHS. If the Government had recognised that, it would very likely have followed that as a group its members would have been given preference for funding the treatment necessary to help put right those wrongs – after all, without yet having those certainties, Jeremy Hunt was prepared to ring-fence part of the Department of Health budget specifically to provide for them (it would appear that he was prepared to use £100m out of the Department of Health budget to help fund this accelerated access).

It is on that basis that, without attempting to resolve the difficult questions that the principles mentioned above may raise in other circumstances, it is clear that (a) had the failures detailed in this Report not occurred, there would have been less need for sofosbuvir-based

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1722 The annex to the submission noted: “*Ministers have given commitments to help, including investigating alleged problems of access to Alpha Interferon for these patients [people with haemophilia]. So far the few cases identified have been readily resolved.*” Submission on Hepatitis C (HCV): The Current Position 23 December 1996 p4, p7 DHSC0004203\_013

1723 Memo from John Horam to Secretary of State for Health 23 January 1997 p1 WITN5294018

1724 Letter from Jeremy Hunt to David Cameron 30 June 2015 p3 CABO0000163\_003. Inferentially, this means the way in which people infected through blood and blood products had been let down by the NHS at the time they were infected, and let down since by much of the response of authority, and had suffered for many years without recognition.

treatments than arose; (b) if it had been appreciated by then, as it should have been, that the infections from blood and blood products were serious failures for which authority was ultimately responsible, those infected by blood and blood products would have had priority for funding; and therefore (c) there should not have been any such difficulty as there was in England in receiving treatment with direct-acting antiviral drugs such as sofosbuvir.<sup>1725</sup>

I acknowledge in reaching this conclusion that funding was tight across government: but this was a question not of extra spending, so much as one of allocating priorities. And it would have been fair as a priority to allocate enough funding to help moderate the harm done to individuals as a result of the several, interconnecting failures that led to their having to live with otherwise relentless infection. Instead, the established basis for allocating when money should as a priority be spent (which was making funding obligatory no more than three months after NICE approved the treatment) was not followed on this occasion, and a delay was authorised. In conclusion, there should not have been the delays in funding that there were.

### Evidence from people who were infected

The Inquiry has received statements from a number of individuals whose antiviral treatment was delayed or denied, which reflects the position outlined above. One witness, Robert, describes not being aware of, or offered, treatment for Hepatitis C until 2006 when he was treated with combination therapy of interferon and ribavirin.<sup>1726</sup> Some patients were also denied treatment based on other factors. Thomas Farrell describes being initially denied treatment with interferon due to being “*too old*”.<sup>1727</sup>

Some people also describe not being able to access DAA treatments. Christopher Meaden describes his mother’s difficulties accessing treatment with interferon, ribavirin and telaprevir in 2013 in Wales. He describes a “*delay due to the Health Board refusing to fund*” the treatment. Cardiff Health Authority refused to pay for her treatment as she did not live in that area. She had to apply to Cwm Taf Health Board who “*took months before they agreed*” to fund her treatment. He describes how this delay increased the risk of his mother developing cirrhosis due to the genotype of Hepatitis C she had.<sup>1728</sup>

Michelle Tolley describes being told by her treating hospital that only eight people were able to receive treatment with DAAs per month. Initially she was eligible for treatment. However, she then was told that due to the hospital losing funding, the number of patients eligible for

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1725 NHS England explains that this would have to have been a government-led initiative: “As a commissioner, NHSE could be in breach of its equality and other statutory duties if it took a decision with the funding it receives to prioritise access to treatment based on how a patient became ill rather than on criteria about their clinical need for treatment. In the event of a Government led initiative where a specific project or remit with specific additional funding was provided to NHSE for this purpose, NHSE would be able to facilitate and support such a scheme.” Written Statement of Claire Foreman para 210 WITN3953001

1726 Written Statement of Robert (ANON) para 25 WITN2258001

1727 Written Statement of Thomas Farrell para 36 WITN0087001

1728 Written Statement of Christopher Meaden pp5-6 WITN2376001

treatment reduced from eight to two and she was no longer able to receive it.<sup>1729</sup> Similarly in Scotland, Kenneth Dyson's wife was unable to access Harvoni treatment while being treated in Edinburgh due to funding constraints across health boards. She had to travel to Monklands Hospital to be treated.<sup>1730</sup>

Mrs D was told that funding meant treatment decisions were made on a month-by-month basis: *“that you wouldn't know who it was going to be until they'd had the meeting that month and decided who was going to get the treatment”*. She said *“I didn't see why on earth I should wait for the treatment, especially as I'd found out that it was the NHS that had actually given me the infection and caused so many medical problems associated with that”*. She found there was no support during the wait, unlike when she had been diagnosed with thyroid cancer: *“This just abandoned me to the fears I had”*.<sup>1731</sup>

One witness describes a contrast between his difficulty in accessing Hepatitis C treatment and that which he received for HIV:

*“I felt that the HCV treatments were seen as a financial issue for Health Trusts and Government funding, rather than the focus being on their treatment value for our condition. I spent many years fighting for treatment for my HCV before I eventually got it ... I found it very hard to bear the fact that although I had been given the virus by the NHS I was being denied treatment for it because I didn't fall under the NICE guidelines. I was just a number on a list, not a person. With HIV, it was different as the doctors wanted me to have medication many years before I agreed to use it.”*<sup>1732</sup>

Witnesses also describe being denied treatment due to not being considered ill enough. One witness describes how her consultant recommended treatment specifically with DAAs due to her also having the autoimmune condition Sjögren's syndrome. She had previously been denied DAAs as her *“liver fibrosis score was not high enough to meet the criteria set by NHS England.”* She was refused treatment with DAAs again and instead offered treatment with interferon and ribavirin, the first course of which had made her very unwell. Eventually she paid for a course of DAA treatment – sofosbuvir and daclatasvir – and managed successfully to clear the virus. She describes the difficulties that attempting to get funding had on her health: *“The anguish of fighting so hard to get NHS funding had a profound effect on my health and caused my mental state to deteriorate.”*<sup>1733</sup> Susan Wathen described requesting Harvoni treatment from her hospital following a discussion with a professor at the 2015 Hepatitis C Trust patient conference. Her hospital subsequently applied to the clinical commissioning group for funding. However this was denied as she was not considered

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1729 Written Statement of Michelle Tolley paras 29-30 WITN0276001. This may have been a reflection of the way in which treatment with DAAs was made available in England through operational delivery networks as described above.

1730 Written Statement of Kenneth Dyson para 28 WITN2129001. Monklands is in Lanarkshire. Edinburgh Royal Infirmary and Monklands Hospital are 40 miles away from each other.

1731 ANON Transcript 10 May 2019 pp92-94 INQY1000008

1732 Written Statement of Paul (ANON) paras 43-44 WITN1003001

1733 Written Statement of ANON paras 23-24 WITN1516001

“*ill enough*” for treatment. She was eventually treated with Harvoni after a two-year delay between diagnosis and receiving treatment.<sup>1734</sup>

In Northern Ireland, Sharon Lowry’s late husband, Richard, became aware of Harvoni in 2014 and was told that he would be suitable for a DAA, but “*You had to go on to a waiting list.*” His MP lobbied on his behalf and then he was accepted for treatment.<sup>1735</sup> Christopher Birtles tried treatment again in 2016: “*when the new Harvoni treatment became available ... They had to apply for funding ... They were not prepared to give it to everybody because of the cost. That was wrong because the health service had caused the HCV problem in the first place.*”<sup>1736</sup>

Others describe the lack of access they had to mental health treatment following treatment with interferon and ribavirin. For example, Neil Cruickshank’s medical records state he experienced “*Interferon induced psychosis*”. He describes not being given access to a mental health team or support during his treatment. He states: “*Whereas I did not face any obstacles in having access to treatment, I do think that because it is recognised that mental illness is a side effect of the treatment, a psychologist and psychiatrist should be available at the Department.*”<sup>1737</sup> John Boakes describes the effect that his first treatment with interferon and ribavirin had on his mental health, including severe mood swings and depression, which was further compounded by subsequent treatments with pegylated interferon and ribavirin. He describes the difficulties getting support for this: “*When I would go to the doctors and explain how I was feeling, so often the response was to increase my dose of anti depressants.*” He describes the importance of mental health support for those with Hepatitis C, alongside treatment for physical symptoms.<sup>1738</sup>

A number of participants described how they felt that they had to fight for treatment or testing, or felt that their loved ones had not been as actively monitored as they would have wished, and have been left with worries that if their concerns had been effectively addressed at the time matters might have turned out better. This emphasises the importance of clinicians and government listening to what patients (often in some distress) are really saying to them and taking what action they can to address this.

### **Current availability of treatment**

The Inquiry obtained evidence from each of the four nations with regards to the current availability of treatment and ongoing monitoring of patients treated for Hepatitis C. In England, the 23 operational delivery networks are responsible for the testing, diagnosis and

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1734 Written Statement of Susan Wathen paras 46-49 WITN1995001

1735 Sharon Lowry Transcript 24 May 2019 p94 INQY1000012

1736 Written Statement of Christopher Birtles para 15 WITN3687001

1737 Written Statement of Neil Cruickshank para 31 WITN2839001, Letter from Dr Henry Watson to Dr Andy Fraser 2 December 2014 p2 WITN2839009

1738 Written Statement of John Boakes para 17, para 51, para 53 WITN2692001

treatment of Hepatitis C.<sup>1739</sup> Treatment services are therefore dependent on the local area, however, broadly patients diagnosed with Hepatitis C are offered a liver fibrosis assessment and subsequently a multi-disciplinary meeting is held to discuss treatment needs prior to treatment with antiviral therapy.<sup>1740</sup> Claire Foreman, of NHS England, stated that treatment is currently available for all those with Hepatitis C in England.<sup>1741</sup> NHS England now provides postal testing.<sup>1742</sup>

In Scotland, treatment is funded by territorial NHS Boards through funding from the core grant received from the Scottish Government as well as under the Hepatitis C Action Plan.<sup>1743</sup> Professor John Dillon stated in his written statement that “*All patients in Scotland have access to treatment with a direct acting antiviral regimen, irrespective of stage of disease or route of infection*” and that no waiting lists for treatment exist in Scotland.<sup>1744</sup> Dr Stephen Barclay noted that almost 90% of those infected with Hepatitis C had been identified and the majority of those had received treatment.<sup>1745</sup>

In Wales, Hepatitis C treatment is commissioned by health boards with funding provided by the Welsh Government. Professor Chris Jones stated that there are currently no restrictions on treatment and currently no waiting lists for treatment.<sup>1746</sup> An oversight group has been set up by the Welsh Government to oversee the elimination of Hepatitis C across the seven Welsh health boards through public awareness and improved access to testing.<sup>1747</sup> Sexual Health Wales provides test and post kits.<sup>1748</sup>

In Northern Ireland, the improvement in waiting times detailed above has been achieved through close working between the commissioning team and the clinical team to reform the pathway for patients. All NICE-approved specialist drug therapies are available.<sup>1749</sup>

## Ongoing monitoring

Evidence provided to the Inquiry demonstrates that a lack of ongoing monitoring is an area of concern for those who were infected with Hepatitis C and have cleared the virus.<sup>1750</sup>

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1739 Written Statement of Mark Gillyon-Powell para 4.1 WITN7740001. Mark Gillyon-Powell is deputy director for HCV Elimination & Health Inequalities in NHS England’s specialist commissioning directorate.

1740 Written Statement of Professor Graham Foster para 19 WITN3042004

1741 Written Statement of Claire Foreman para 190 WITN3953001

1742 hepctest.nhs.uk

1743 Written Statement of Professor John Dillon p2 WITN4062001, Written Statement of Samantha Baker para 6 WITN0713010. Professor Dillon is professor of hepatology and gastroenterology at the University of Dundee. Samantha Baker is the team leader within the Scottish Government with overall responsibility for infected blood.

1744 Written Statement of Professor John Dillon para 7 WITN4062001

1745 Written Statement of Dr Stephen Barclay para 3a WITN7739001. Dr Barclay is a consultant gastroenterologist at Glasgow Royal Infirmary with a special interest in liver disease.

1746 Written Statement of Professor Chris Jones paras 11-14 WITN4065001

1747 Written Statement of Professor Chris Jones para 2 WITN4065025

1748 shwales.online

1749 Written Statement of Caroline Leonard para 7.1 WITN3449023

1750 See the chapter on *People’s Experiences*.

The Expert Group on Hepatitis advised the Inquiry that successful treatment for Hepatitis C can considerably reduce (by approximately 70%), but not eliminate the risk of cancer. The experts explained that the major factor determining any long-term impact of Hepatitis C on a person's health is the degree of liver fibrosis at the time when the Hepatitis C polymerase chain reaction ("PCR") test became negative. The experts therefore said that people with significant fibrosis or cirrhosis are likely to require lifelong surveillance for the risk of hepatocellular carcinoma ("HCC"), with six-monthly testing usually involving an ultrasound of the liver and an alpha fetoprotein ("AFP") blood test. They advised that those without evidence of liver scarring and no other conditions likely to affect the liver may be discharged from specialist care.<sup>1751</sup>

In his second written statement, Professor Michael Makris recommends that patients with an inherited bleeding disorder infected with Hepatitis C, including those who had successfully cleared the virus, should be reviewed by a liver specialist at least once.<sup>1752</sup> He explains that many of the patients with bleeding disorders treated over the last 35 years, especially prior to the last decade, will have been treated through haemophilia centres rather than by a hepatologist. He cites two studies – from the Angelo Bianchi Bonomi Hemophilia and Thrombosis Center in Milan and the Van Creveldkliniek Haemophilia Center in Utrecht – demonstrating persisting liver damage in those who had been infected through blood products and successfully cleared Hepatitis C. The Milan study screened 119 people with haemophilia who had cleared Hepatitis C and found *“Twenty-one patients (18%) had evidence of advanced fibrosis/cirrhosis and 51 (44%) had evidence of fatty infiltration (steatosis) in their liver.”*<sup>1753</sup> The Utrecht study reported that *“Of 199 individuals with SVR,<sup>1754</sup> 97 were cured with interferon-based regimens and 102 with DAA after median infection durations of 29 and 45 years, respectively. At the end of follow-up, respectively, 21% and 42% had advanced fibrosis or cirrhosis.”* The authors concluded that: *“Successful HCV treatment does not eliminate the risk of liver-related complications in persons with inherited bleeding disorders. Due to higher baseline risk, incidence was higher after DAA than interferon-based SVR. We advise continuing HCC surveillance post-SVR in all with advanced fibrosis and cirrhosis.”*<sup>1755</sup>

Professor Makris therefore recommends that patients with an inherited bleeding disorder who have cleared Hepatitis C should be seen by a consultant hepatologist and have blood tests, an ultrasound scan and a fibroscan. No long-term follow-up is recommended where

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1751 Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p30, p58, pp67-68 EXPG0000001. AFP is produced by certain tumours and diseases of the liver.

1752 Written Statement of Professor Michael Makris p5 WITN4033023. Professor Makris was in practice as a consultant haematologist at Sheffield, and is now editor-in-chief of the journal *Research and Practice in Thrombosis and Haemostasis*.

1753 Written Statement of Professor Michael Makris p3 WITN4033023, La Mura et al *Residual burden of liver disease after HCV clearance in hemophilia: a word of caution in the era of gene therapy* Blood Advances October 2023 WITN4033024

1754 “Sustained virological response” – ie they had “cleared” the virus.

1755 Written Statement of Professor Michael Makris pp3-4 WITN4033023, Isfordink et al *Liver-related complications before and after successful treatment of chronic hepatitis C virus infection in people with inherited bleeding disorders* Haemophilia June 2022 pp1-2 WITN4033025



no liver damage is evident. Where patients have no signs of advanced fibrosis/cirrhosis but have abnormal liver enzymes, the cause of these should be assessed and they should be given advice on lifestyle factors to minimise the risk of liver failure.<sup>1756</sup>

He recommends that patients with advanced fibrosis or cirrhosis are entered into a hepatocellular screening program, with six-monthly ultrasound scans and regular hepatology follow-up to detect early signs of liver failure. He states that *“The chances of success in the treatment of hepatocellular carcinoma depends on how early it is diagnosed, so every attempt should be made for early identification.”* He notes that *“If surveillance is required, there should be a named doctor/team responsible for making sure it takes place on time”* and that those with an inherited bleeding disorder who have had Hepatitis C should be seen by a consultant hepatologist, rather than a more junior member of staff.<sup>1757</sup> Given the particular complexities infected people with inherited bleeding disorders present, and a need to have some understanding of the historical context, I agree with what Professor Makris says.

The Inquiry has received statements from each of the four nations regarding the monitoring of individuals who have had a diagnosis of Hepatitis C. Professor Graham Foster responded to the concerns about lack of consistency in monitoring in England as follows:

*“There are European guidelines on the management of hepatitis C that include recommendations on appropriate follow up. In my clinical experience patients differ greatly in their desire to undergo long-term follow up with some preferring to accept a low risk of future complications rather than to attend for regular scanning and others wishing to undergo regular review, even though the long-term risk is negligible. It is my opinion that these decisions are best made during consultations between the patient and the local medical team and that the European guidelines mee[t] the need for appropriate evidence based guidance. We have no plans to standardise guidance further as best practice is to develop an individualised approach in consultation with the patient.”*<sup>1758</sup>

The guidelines from the European Association for the Study of the Liver include:

- (a) Patients with advanced fibrosis or cirrhosis who achieve a sustained virological response must remain under surveillance for hepatocellular carcinoma every six months by ultrasound, and for oesophageal varices by endoscopy if varices were present at pre-treatment endoscopy. Cofactors for liver disease may result in additional assessments.
- (b) Patients with advanced fibrosis or cirrhosis who are untreated or for whom treatment failed should have ultrasound surveillance every six months.

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1756 Written Statement of Professor Michael Makris p4 WITN4033023

1757 Written Statement of Professor Michael Makris p4, p2, p5 WITN4033023

1758 Written Statement of Professor Graham Foster para 25 WITN3042004, European Association for the Study of the Liver *EASL Recommendations on Treatment of Hepatitis C* Journal of Hepatology 2018 RLIT0001729

- (c) Patients with no to moderate fibrosis who are untreated or for whom treatment failed should be regularly followed up.
- (d) Patients with no to moderate fibrosis who achieve a sustained virological response and have cofactors for liver disease (eg Type 2 diabetes, obesity or excess alcohol consumption) should be “*carefully and periodically*” subjected to a thorough clinical assessment, as required.
- (e) Patients with no to moderate fibrosis who achieve a sustained virological response should be discharged provided they have no other cofactors for liver disease, such as Type 2 diabetes, obesity or excess alcohol consumption.<sup>1759</sup>

It is therefore important for patients to know whether they were found to have fibrosis or cirrhosis.

Individuals diagnosed with Hepatitis C in Scotland undergo either blood or imaging-based assessments to ascertain the stage of their disease. Those without cirrhosis are treated and discharged and those with cirrhosis are treated and undergo a review every six months to monitor for complications of cirrhosis. This involves an ultrasound and blood test for AFP. For those with gastrointestinal varices, an endoscopy is done every three years. Patients who have successfully cleared Hepatitis C – demonstrated by a sustained virological response – do not have any longer-term follow-up unless there is evidence of liver damage.<sup>1760</sup> In response to Professor Makris, Dr Barclay noted that patients with bleeding disorders who have undergone Hepatitis C treatment in Scotland would not solely have been treated by their haemophilia centres, and would have undergone a liver assessment. Therefore, he thought the concerns expressed by Professor Makris were not applicable in Scotland.<sup>1761</sup>

Monitoring of patients in Wales is dependent on the nature of the damage done by Hepatitis C prior to treatment. Professor Jones notes that patients are discharged if there is minimal liver damage, whereas those with advanced liver disease will be monitored by a hepatology clinic, including having regular scans.<sup>1762</sup> Vaughan Gething notes in his statement that “*patients with such conditions such as liver failure, and/or hepatocellular carcinoma, oesophageal varices/variceal haemorrhage, significant fibrosis or cirrhosis would be under the care of a hepatologist or gastroenterologist and would have individual clinical risk assessments to inform further management taking into consideration patient wishes.*”<sup>1763</sup>

Describing the situation in Northern Ireland, Dr Joanne McClean notes that “*HCV treatment has been predominantly delivered through specialist hepatology services*” in Northern

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1759 European Association for the Study of the Liver *EASL Recommendations on Treatment of Hepatitis C* Journal of Hepatology 2018 p4, pp42-43 RLIT0001729

1760 Written Statement of Professor John Dillon paras 8-9 WITN4062001

1761 Written Statement of Dr Stephen Barclay p3 WITN7739001

1762 Written Statement of Professor Chris Jones p3 WITN4065001

1763 Written Statement of Vaughan Gething para 29 WITN5665001

Ireland.<sup>1764</sup> Caroline Leonard says that patients who have a fibroscan suggestive of advanced fibrosis or cirrhosis are kept under long-term review at the liver clinic, with an ultrasound and blood test for AFP every six months and a six-monthly clinic review.<sup>1765</sup>

## Commentary

On behalf of a large group of people who were infected with hepatitis through transfusions, Leigh Day solicitors submitted to the Inquiry that one of the most important issues for them in relation to their treatment was their ability to access monitoring and follow-up care for Hepatitis C (and related symptoms and conditions) after they achieved a sustained virological response, and had thus apparently “cleared” the virus. This was particularly important to them, given their very reasonable anxieties about the harm long-untreated Hepatitis C may have done to their bodies, and their increased risk of developing end-stage liver disease or hepatocellular carcinoma. *“The Hepatitis Experts accurately described these services as ‘patchy’ across the UK, which entirely reflects the experiences of our CPs [core participants], many of whom have simply been discharged from any ongoing care or monitoring following achievement of SVR. Currently there is no consistent clinical practice, and some patients receive no clinical surveillance.”*<sup>1766</sup>

In February 2020 at the end of the hearings with these experts I said:

*“I would like to draw the attention publicly now of NHS England and hospital trusts and boards throughout the country to the fact that the need for specialist treatment by professionals who have a special understanding of infected blood and blood products has not gone away, now that there is greater success in treatment of the underlying conditions, that there is a need to ensure that the standards of follow-up of those who have cleared hepatitis C but have been left with a compromised liver are maintained in accordance with what the experts have set out this week.”*<sup>1767</sup>

Those words remain wholly appropriate.

The consistent delivery of appropriate follow-up monitoring is a legitimate concern. For this reason, I recommend that those bodies responsible for commissioning hepatology services in each of the home nations should publish the steps they have taken to satisfy themselves that the services they are commissioning meet the particular needs of this group of people harmed by NHS treatment, including those with bleeding disorders whose treatment for Hepatitis C was not managed by hepatologists.

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1764 Written Statement of Dr Joanne McClean para 6 WITN7311008. Dr McClean is director of public health in the Public Health Agency.

1765 Written Statement of Caroline Leonard para 9.1 WITN3449023

1766 Written submissions on behalf of the core participants represented by Leigh Day 16 December 2022 p200 SUBS0000059

1767 Sir Brian Langstaff Transcript 28 February 2020 pp177-178 INQY1000054

## Palliative care

Access to palliative care for those infected by NHS blood and blood products has proved wanting. The effect of this has been to compound the harm already experienced as a result of NHS treatment.

Palliative care can be confused with “end of life” care. It may include this, but is much broader in scope and intent – and indeed, the condition for which it is provided may not necessarily be terminal. It is defined by the World Health Organization as “*an approach that improves the quality of life of patients – adults and children – and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.*”<sup>1768</sup> Whilst inclusive of end of life care, palliative care can also be provided in parallel to curative treatments when the prognosis is uncertain.<sup>1769</sup> The World Health Organization now defines a set of principles that constitute appropriate palliative care. In addition to the above, good care includes support systems for patients and the family, delivered as a team approach.<sup>1770</sup>

The funding and commissioning of palliative care services varies throughout the UK. Whilst in England it is overseen by integrated care boards and local authorities, in Scotland responsibility for funding sits with integration authorities. In Wales palliative care is not fully commissioned since the health boards work with the voluntary sector. Northern Ireland has the Palliative Care in Partnership Programme with shared principles including that palliative care is not just about the last weeks or days of life. The existence of multiple information systems, which are frequently not connected, hampers straightforward data collection and analysis, and makes it challenging to draw any firm conclusions around expenditure and resources.<sup>1771</sup> The Inquiry has, however, received a range of evidence about people’s experiences of palliative care and an expert report into palliative care. Several themes emerge from this evidence which are explored further below.

### Palliative care for people with Hepatitis C and liver disease

The Expert Report on Hepatitis referred to variability throughout the UK in referral to specialist palliative care and access to palliative care services for patients with chronic liver disease.<sup>1772</sup>

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1768 World Health Organization Fact Sheet on Palliative Care 1 June 2023 RLIT0002369

1769 Expert Report to the Infected Blood Inquiry: Palliative Care in Advanced Liver Disease February 2022 p5 EXPG0000043

1770 World Health Organization Fact Sheet on Palliative Care 1 June 2023 RLIT0002369

1771 Expert Report to the Infected Blood Inquiry: Palliative Care in Advanced Liver Disease February 2022 p7 EXPG0000043, Review of Specialist Palliative Care Services in Wales 2010-2021 July 2021 p44 RLIT0002376, Northern Ireland Palliative Care in Partnership Programme Mandate April 2023 p3 RLIT0002375

1772 Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p37 EXPG0000001

In some cases, palliative care services appear to have struggled to provide adequate care for infected persons suffering from Hepatitis C and non-cancer life-threatening illness. Rachael Watkins described requesting hospice care for her mother, but being refused “on the grounds of not understanding how to care for someone with liver disease. We also requested palliative care, but this request was declined by both the NHS and the Macmillan nurses, as they did not know how to cope with a hepatitis patient. In the end, nobody came and nobody turned up.”<sup>1773</sup>

Alison Purseglove described a similar situation relating to her husband Ian. She had worked for the ten years before Ian’s death in the fields of palliative and end of life care. Thus:

*“in the two years before his death, I could tell that he was dying. This appears to have escaped the notice of the consultants ... who were fixated on spotting when the transplanted liver would succumb to reinfection. This had not happened to a significant extent, at the time of death (although the post mortem did show cirrhosis). However, in the last three months, the decline was very rapid and Ian was admitted to hospital where he died before a diagnosis had been agreed. The hospital was unprepared for the death and as a result it was, to my sadly expert eyes, extremely badly managed, protracted and distressing for both Ian and me.”*<sup>1774</sup>

Kathryn Johnson described how staff in the hospice looking after her sister Jane Chapman said they couldn’t carry out paracentesis at the hospice as they lacked the expertise to perform the procedure so Kathryn had to persuade them to transfer Jane to the nearby hospital to drain the fluid.<sup>1775</sup>

One woman described similar incidents following fluid build-up in her husband’s stomach:

*“On 15 April 2019 we had a meeting with the Macmillan nurses, who asked the doctors if his stomach could be drained as he’s been previously denied the opportunity as it may harm his other organs, but she did not come back with a clear answer. This was the second time [my husband] had not been given the opportunity to be drained. I do believe the nurse asked the doctors about the draining, but I do also wonder whether they knew about [my husband’s] HCV. I had a friend of a friend who had liver cancer and the nurses would drain him twice a week. I remember, [my husband] went as far as to say ‘Even if my other organs get damaged, I am willing to take the risk, as I cannot take being this uncomfortable anymore, I just want it drained off.”*<sup>1776</sup>

Whilst the diagnosis of incurable liver cancer has traditionally been a trigger to prompt referral to specialist palliative care, patients with advanced decompensated cirrhosis, who

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1773 Written Statement of Rachael Watkins para 41 WITN3281001

1774 Written Statement of Alison Purseglove para 19 WITN3056001

1775 Written Statement of Kathryn Johnson para 92 WITN3567001. Paracentesis is the removal of excess fluid from the abdomen.

1776 Written Statement of ANON paras 70-71 WITN3566001

may have a similar prognosis, have in the past been referred very late, often in the last days of life. As Dr Benjamin Hudson noted, palliative care in liver disease is a developing subspecialty: *“if you go back as short as ... five, six years, [it] wasn't really a thing. It wasn't really considered.”*<sup>1777</sup> Advanced liver disease is characterised by a multitude of distressing physical and psychological symptoms, poor quality of life, frequent hospital admissions and a high burden on caregivers. Palliative care, delivered across a variety of settings, can help alleviate distress and is of demonstrable benefit to patients and carers. Despite a growing body of evidence supporting the integration of palliative care in the management of advanced liver disease, at present it is not routinely used in this patient group.<sup>1778</sup>

There are currently no repositories of data providing objective information or detail about what palliative care is provided for people with advanced liver disease receiving care in different parts of the UK. As there is no national consensus on what constitutes a standard model of care for people with advanced liver disease and palliative care needs, palliative care provision both at core and specialist level is dependent upon individual clinicians in all settings being interested in providing this care themselves, or requesting collaborative support from specialist palliative care teams.<sup>1779</sup>

Perhaps unsurprisingly, inconsistencies have emerged. The thread running through the expert evidence obtained by the Inquiry is that the provision of palliative care for patients with advanced liver disease remains patchy across the UK. It is contingent upon local interest, expertise and resources. The patient and carer experience of healthcare for advanced liver disease frequently remains poor, reflecting an illness trajectory typically characterised by recurrent and prolonged unplanned hospital admissions, a high burden of untreated physical and psychological symptoms, considerable social stigma and sub-optimal end of life care.<sup>1780</sup>

In Dr Hazel Woodland's opinion, the problem is one of resourcing, and is not specific to palliative care, but applies to care for hepatology patients generally.<sup>1781</sup> Dr Fiona Finlay noted that access differs across the country depending upon whether the patient has a hospice nearby or whether there is in reach to their local hospital service.<sup>1782</sup> The Expert Report on Palliative Care in Advanced Liver Disease noted that patients with advanced liver disease seldom receive palliative care, citing a study of patients dying from liver disease at a UK transplant centre which reported that only 19% of patients received palliative care, on

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1777 (Dr Benjamin Hudson) Palliative Care Expert Panel Transcript 4 March 2022 p81 INQY1000190. Dr Hudson is a consultant hepatologist with an interest in palliative medicine, and lead of the national special interest group on palliative medicine of the British Association for the Study of the Liver.

1778 Expert Report to the Infected Blood Inquiry: Palliative Care in Advanced Liver Disease February 2022 p6 EXPG0000043

1779 Expert Report to the Infected Blood Inquiry: Palliative Care in Advanced Liver Disease February 2022 p13 EXPG0000043

1780 Expert Report to the Infected Blood Inquiry: Palliative Care in Advanced Liver Disease February 2022 p19 EXPG0000043

1781 (Dr Hazel Woodland) Palliative Care Expert Panel Transcript 4 March 2022 p30 INQY1000190. Dr Woodland is a consultant hepatologist with an interest in palliative medicine, who has completed research focused on improving care for patients with advanced liver disease.

1782 (Dr Fiona Finlay) Palliative Care Expert Panel Transcript 4 March 2022 pp33-34 INQY1000190

average only four days before death.<sup>1783</sup> In Professor Charles Hay’s words, end-of-life care is a specialised area of medicine and nursing, *“It can be excellent but in other cases is not provided at all.”*<sup>1784</sup>

The evidence of Justine Gordon-Smith and her sisters is a vivid illustration of what can happen in the absence of an adequate palliative care plan. Their father Randolph Peter Gordon-Smith, known as Peter, died on 24 July 2018. As a consequence of his treatment with Factor 8, Peter contracted Hepatitis C, which later developed into hepatocellular cancer. A huge responsibility for nursing Peter after the chemotherapy which followed diagnosis fell upon his daughters, who became his carers, with ongoing effects on their ability to earn or progress in their careers. Their efforts were recognised repeatedly in medical accounts of his progress.<sup>1785</sup> It became apparent in early 2017 that attempts to neutralise the cancer by targeted chemical treatment (“TACE”)<sup>1786</sup> had failed, and the cancer was spreading. The recollection of Justine is that instead of involving Peter and his family in an open discussion about his prognosis, he was bluntly informed that he would receive no further treatment and had only six to nine months to live.<sup>1787</sup> The medical notes record two relevant conversations between Peter and his oncologist, of the 2 May and 12 May 2017. Following the discovery that the cancer had spread, the first was to *“discuss alternative treatment options”*. Though treatment could prolong life for perhaps two to three months, though even with treatment prognosis was thought to be six to 12 months, the treatment carried *“potentially significant toxicity”* such that the oncologist was concerned it *“would harm his quality of life for potentially marginal gains”*.<sup>1788</sup> Nonetheless, it was noted that his daughters were very keen that he should be considered for any active treatment including participation in any relevant trials. The second was to review what, in the light of the first meeting, should be done. The oncologist recorded that at the second meeting, with Peter and his daughters, it was agreed that focussing on symptom control would be a more appropriate course of action than taking the only available drug which might prolong life a little. Under a paragraph headed *“Recommendations”* the letter (to his GP) began by saying *“We had a discussion about the role of the community palliative team which he is considering”* and recorded Peter’s view that *“he does not have any particular symptoms to palliate at present but recognises that things may become more difficult in the future.”*<sup>1789</sup>

One of her sisters says that at the point that it was realised that the cancer was spreading *“We felt completely let down by the NHS at that point. There was no follow up from palliative care at that point, we were just left in limbo.”*<sup>1790</sup> With no referral to palliative care, the family had to make arrangements with Peter’s GP. After some persistence, a morning care

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1783 Expert Report to the Infected Blood Inquiry: Palliative Care in Advanced Liver Disease February 2022 p6 EXPG0000043

1784 Written Statement of Professor Charles Hay para 188.5 WITN3289039

1785 NHS Lothian Patient Record of Randolph Gordon-Smith WITN6932030

1786 Trans Arterial Chemical Embolisation.

1787 Written Statement of Justine Gordon-Smith para 37 WITN2632001

1788 NHS Lothian Patient Record of Randolph Gordon-Smith pp9-11 WITN6932030

1789 NHS Lothian Patient Record of Randolph Gordon-Smith pp13-14 WITN6932030

1790 Written Statement of R Gordon-Smith paras 32-33 WITN2633001

package began in June 2017.<sup>1791</sup> The family were assigned a palliative care nurse who put Peter on steroid tablets, although he might well have had a genetic allergy to them. She says it was his decision to accept them. It turned out badly. It led to what Justine described as *“the beginning of our yearlong living hell caring for our beloved Daddy.”*<sup>1792</sup> Following a formal complaint, Peter’s care was moved to a different palliative care provider and his care improved, but the family continued to have to organise additional services.<sup>1793</sup>

Peter moved into a hospice part-time in his final months.

Since her father’s death, Justine has suffered from complex post-traumatic stress, delaying a return to a research project, from which she had taken a two-year break.<sup>1794</sup> One of her sisters had to reduce her hours and had many absences from work to care for him.<sup>1795</sup> The family lost a five figure sum in wages. Justine reflects: *“We began to look into this and realised that not once during the palliative stage of Dad’s life, had any medical professional mentioned or discussed how the Hepatitis C virus would impact on our Dad ... The point we wanted to make and keep feeling that we have to make is that HCV infection and its impact has to be central to all palliative care considerations.”*<sup>1796</sup> Julia reflected that *“sufferers of contaminated blood ... should have been properly taken care of when they had a chance to enjoy some quality of life ... It was all too little too late.”*<sup>1797</sup> Though palliative care is recorded as having been discussed, in May 2017, the experience of Peter, as described by his daughters, supports the view that the earlier palliative care pathways can be discussed with patients suffering from advanced liver disease which may be terminal, the better.

Seamus Conway’s siblings described the difficulty of securing adequate pain relief for him: *“Shea was admitted to hospital at the end of April in horrendous pain. We had to fight for the appropriate pain relief for him.”* His haemophilia doctor sent word that if he said it was not a bleed then more than likely it wasn’t and he needed pain relief. As a family they had to watch him *“crying out in pain”* and *“suffering terribly”*. Patricia said: *“It was terrible and the memory haunts me.”*<sup>1798</sup>

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1791 Written Statement of Justine Gordon-Smith para 85 WITN2632001

1792 Written Statement of Justine Gordon-Smith para 39 WITN2632001

1793 Written Statement of Justine Gordon-Smith para 51 WITN2632001, Written Statement of Julia Gordon-Smith para 182, para 184 WITN2664001

1794 Written Statement of Justine Gordon-Smith para 34, para 80 WITN2632001

1795 Written Statement of R Gordon-Smith para 60 WITN2633001

1796 Written Statement of Justine Gordon-Smith para 110 WITN2632016

1797 Written Statement of Julia Gordon-Smith para 181 WITN2664001

1798 Written Statement of Paula McLaughlin para 18 WITN2927001, Written Statement of John Conway paras 21-22 WITN2964001, Written Statement of Rosemary Devine para 25 WITN2742001, Written Statement of Maria Conway para 20 WITN2739001, Written Statement of Christina McLaughlin para 188 WITN2778006, Written Statement of Patricia Kelly para 24 WITN2765001, Christina McLaughlin, John Conway, Patricia Kelly Transcript 23 May 2019 p135 INQY1000011



## Palliative care for patients with HIV and AIDS

HIV was a life-threatening disease. In the days before highly active antiviral therapy began<sup>1799</sup> it called out for palliative care.

Though palliative care should have been an integral part of the care pathway in the 1990s, it was often riven by stigma. Debra Pollard, lead nurse specialist at the Royal Free Haemophilia and Thrombosis Centre where she has worked since 1992, provided evidence of her close liaison with palliative care but noted that owing to the stigma attached to HIV, palliative care and some hospices would initially refuse to accept HIV patients.<sup>1800</sup> That is precisely what happened to Ken Milne, who was refused a place at Canterbury Hospice because he was HIV positive.<sup>1801</sup> Being one of the first people in the country to be infected with HIV, Mark Newton also found that he had no options for end of life care.<sup>1802</sup>

Admission to a palliative care programme did not guarantee non-prejudicial treatment. Kathryn Reeve explains how a hospice treating her uncle Graham Fox told the family to tell people he had lymphoma and not HIV or AIDS because of the stigma that was attached to it at the time: *“Some medical professions wouldn’t do certain things for my uncle as they were scared of being infected by him, therefore my mother had to do it for him. She took better care of him than the medical staff at the hospitals.”*<sup>1803</sup>

## Poorly delivered palliative and end of life care

A common theme in people’s experiences of palliative and end of life care was poor communication with the patient and their family. One woman described how *“The hospital staff never discussed [my husband’s] illness or life expectancy with me. There was very poor communication. I understand he was receiving palliative care in the last week of his life. This was never explained.”*<sup>1804</sup>

In written and oral evidence, Amanda Beesley described inadequate comprehensive care for her husband Andrew:

*“We found the treatment we received at St Michael’s Hospice in Basingstoke appalling. I think Andrew was admitted there after his pancreatitis as a half-way to returning home. The staff displayed little empathy towards us and no understanding of Andrew’s health status at that time. Within an hour or so of being admitted, he started to pass blood in his urine, which was most likely a haemophilia related problem. He had not had this happen before, so we were worried about it. I asked the hospice staff to contact the haemophilia doctor, but they would not. They treated me as though I was exaggerating the urgency*

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1799 In around the mid-1990s.

1800 Written Statement of Debra Pollard para 102 WITN3094028

1801 Written Statement of Barbara Milne para 47 WITN4580001

1802 Written Statement of Judith Holdsworth para 14 WITN7024001

1803 Written Statement of Kathryn Reeve paras 14-15 WITN1484001

1804 Written Statement of ANON para 41 WITN0906001

*of the situation and were trying to talk to me about accepting that Andrew was terminally ill instead of getting him the medical attention he required. At this stage, he was not dying but I was frightened that he could die of a bleed if not treated. I cannot describe the anguish I felt trying to convince them to get appropriate help.”<sup>1805</sup> “They just kept saying to me things along -- I had got to accept that my husband was going to die, you know, he was poorly, he was going to die and I couldn’t just keep looking for treatment for him sort of thing. I was like, ‘This is an acute haemophilia problem that maybe he -- because we didn’t know what was happening. Maybe he could die of this today. He doesn’t need to die today of this. Get me the treatment. Get him the treatment. Get somebody here.’ I don’t know quite how I managed it in the end, but we did actually see a haemophilia doctor, who then dealt with it and it was okay. But the level of ignorance about haemophilia and HIV and what we were going through was just incredible, really, and just again this always having to fight, fight with the medical professionals to get treatment that you need and having to understand and know. I mean, you had to be knowledgeable yourself to try and get the treatment right, because nobody seemed to be joining up the dots and nobody seemed to be offering comprehensive care.”<sup>1806</sup>*

Another woman described a lack of communication from a palliative care nurse on a home visit:

*“I had been refusing [respite] because I really didn’t want anyone else looking after him, however [my husband’s] mum persuaded me, saying that it would be better to stop me from burning out so I agreed. Shortly after, a nurse came over at 10pm at night. At this point [my husband] was in a hospital bed, so I took her through to where he was. She reassured me that she would look after him and keep all the doors open so I could hear. She promised that if there were any problems she would come straight through and let me know. I had made this nurse swear that she would tell me if there was a problem. I went through and I must have fallen asleep because the next thing I knew, I could hear my husband screaming his head off.”*

She also heard voices she did not recognise and found that the nurse had called in her colleagues for help rather than coming straight through: *“Her response to me was that his breathing was a bit funny. I asked her to clarify this because frankly this was the first time she had met [my husband], she didn’t know what his breathing was normally like. They were moving him up the bed but none of them had given him the proper medication to do so and this was why he was screaming. They gave him the medication AFTER they finished working on him.”<sup>1807</sup>*

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1805 Written Statement of Amanda Beesley para 85 WITN1090001

1806 Amanda Beesley Transcript 16 October 2019 pp148-149 INQY1000042

1807 Written Statement of ANON paras 45-47 WITN2264001

One woman described missed opportunities following a failure to communicate useful information until the very late stages of her mother's illness:

*“No counselling or psychological support was ever made available to my mother when she was diagnosed with HCV or the resulting liver tumour. She was not given any leaflets, booklets or advice on how she could manage her terminal illness until a nurse handed her a pile of leaflets about HCV, liver cancer, coping with a terminal illness, details of support groups and a diet plan at an oncology appointment six months later. By this time she only had weeks left to live and so, despite following the high protein diet plan, she could not access the drop-in support group that was mentioned because by then she was too unwell to attend. It seemed desperately unfair that she was only given this information when she was weeks from death and had not known about the support available for months and months.”*<sup>1808</sup>

Two other witnesses explained the consequences of such late delivery of palliative care: *“We were completely oblivious as to the true nature of his illness and the fact that he would never leave hospital before his death. He was not given the opportunity to get his affairs in order as a result.”*<sup>1809</sup> Palliative care *“was only ever explained to me at 2 or 3pm the day [my husband] died. This is why his death was such a shock to the family and myself. We didn't have the chance to say goodbye, I feel I was robbed of that opportunity.”*<sup>1810</sup>

Pe Rae described how insensitive communication of terminal illness affects those receiving the news: *“One day I went in to hospital to see him and I knew something was wrong. He almost didn't recognise me. I asked the doctor working on the wing (not his usual doctor) what was happening and he said ‘we'll put him on the pathway now’ and walked off. I didn't know what this meant. I found this an unbelievable way to be told my husband was not stabilising but dying.”*<sup>1811</sup>

Poor communication about palliative and end of life care went hand-in-hand with poor planning and delivery. Ira Hill described *“mis-communication, excessive changes and numbers of care staff coming into the home, delays in getting services to become available, lack of qualified staff, untrained care staff, no coordination between acute medical teams and palliative care and no communication between hospital and community staff.”* Instead of a joined up, holistic service instilling confidence in the patient, Ira's husband, Steve, experienced *“a desperate time ... as services that were acutely required were not forthcoming, conflicting views as to what would be helpful leading to a lack of trust in services and totally contradicting advice regarding treatments planned which added to the lack of trust.”*<sup>1812</sup>

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1808 Written Statement of ANON para 39 WITN1819001

1809 Written Statement of ANON para 44 WITN0988001

1810 Written Statement of ANON para 22 WITN0640005

1811 Written Statement of Pe Rae para 52 WITN1962001, Pe Rae and Bronwyn Rae-Le Bourn Transcript 6 June 2019 pp34-36 INQY1000015

1812 Written Statement of Ira Hill para 32 WITN7431001

Paula Watt had a similar experience with her brother, Gary: *“I believe his palliative care was very poor; there was no formal end of life plan, no pain relief, it was shocking. His care was left pretty much to my mother.”*<sup>1813</sup>

Multiple witnesses describe how those they cared for were left without any palliative or end of life care at all, and the toll this took on the infected person and themselves. Julia Borthwick described how her father was sent home by a hospital with no medication, no counselling and no palliative care: *“My mother had the unenviable task of taking care of my father whose physical and mental condition slowly declined. This had a terrible impact on my mother. Prior to this our grandmother was living with us and my mother had to manage two jobs to pay all the bills. This all changed when my mother had to give up work to care for my father. In consequence, my grandmother had to move into one of her other daughter’s homes.”*<sup>1814</sup>

Linda Cannon described being “cast adrift” after a doctor recommended that a Do Not Resuscitate order be given to her husband, Billy: *“We were told on a Friday night and I still had to think about running the business – my husband’s business – the following week ... The only support I had was from my family ... The end was imminent. 2 weeks later he passed away. We had spent 4 weeks trying to get him care and support when he was dying ... Right at the end of Billy’s life, our GP arranged for Macmillan Nurses to come out, but they only came once; Billy died before they came back again.”*<sup>1815</sup>

One woman described being a full-time carer for her mother for six months: *“I was offered respite once, about a month before [my mother] died, but I did not want to leave her. As she was bedbound, I set up her bed in the front room of the house, as I had already converted the ground floor bathroom into a wet-room for her. I had even considered having a lift installed in the house but my mother became unresponsive for the final time so I took her back to the hospital. She passed away a few days later.”*<sup>1816</sup>

Other witnesses fared no better. Dr Sarah Gough noted that *“We never received any input from palliative care despite my father’s very poor prognosis.”*<sup>1817</sup> One woman found that when her brother was dying *“There was no palliative care in place; none of the medical team spoke to our mother, nor me or my sister.”*<sup>1818</sup> Fraser Bissett described how *“No one ever came round to help ... No nurse visited us, we only ever had a Marie Curie nurse come over when my father was on his deathbed. He never was offered any psychological support.”*<sup>1819</sup>

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1813 Written Statement of Paula Watt para 25 WITN3855001

1814 Written Statement of Julia Borthwick para 24 WITN1629001

1815 Written Statement of Linda Cannon paras 30-31, para 52 WITN2100001

1816 Written Statement of ANON para 39 WITN2771001

1817 Written Statement of Dr Sarah Gough para 31 WITN1246001

1818 Written Statement of ANON para 14 WITN3028001

1819 Written Statement of Fraser Bissett para 6 WITN2090001

## Good palliative care

In line with the picture painted by the expert evidence of a patchy system across the UK, some witnesses reported experiencing good palliative care. Their evidence demonstrates how valuable it can be to both patients and the bereaved. Manuela Sams describes how they were told her father Federico was receiving “*gold standard*” palliative care and Macmillan Cancer Support organised a holiday, psychological support, respite care and relaxation classes. Federico lived a few months longer than the prognosis he had received.<sup>1820</sup> William Hewitt explained how he is eternally grateful to the two nurses who sat and held his father’s hands for the last hours of his life. The nurses also attended his funeral.<sup>1821</sup>

Susan Oliver talked about the positive support she received for her mother: “*On 23 August 2016 at St James hospital, my mother was referred to a Macmillan nurse. On 1 September, the hospitals began to put support in place. She was approaching the end stages. The nurses were wonderful. In the last two weeks of her life, the care team were coming in 4 times a day to see to her. They kept her looking smart. Her wish was to remain at home.*”<sup>1822</sup>

## Current position

The evidence obtained by the Inquiry from the four nations of the UK demonstrates that palliative and end-of-life care for patients with advanced liver disease is continuing to develop organically. In Scotland, implementation of standards of care which are being formulated by professional societies will be via local bids for funding services, unless there is a directive government policy.<sup>1823</sup>

Northern Irish patients with advanced liver disease can already be referred for assessment, advice and provision of palliative care at any point in their clinical pathway. A regional Palliative Care in Partnership approach is in place, with leadership from the Department of Health via the Palliative Care in Partnership Programme Board, with membership from the Public Health Agency, all health and social care trusts, hospices, charities, independent sector providers and general practice. The regional focus is on the early identification of people who are likely to be in their last year of life, the assignment of palliative care key-workers and improving palliative care services in general.<sup>1824</sup>

In England, palliative and end of life care is delivered by, and across a range of, local and national statutory and voluntary organisations. The National Palliative and End of Life Care Partnership is a broad partnership of national organisations (including NHS England), across

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1820 Written Statement of Manuela Sams paras 23-24, para 33 WITN4352001

1821 Written Statement of William Hewitt paras 42-43 WITN4645001

1822 Written Statement of Susan Oliver para 20 WITN0993001

1823 Written Statement of Professor John Dillon para 9.1 WITN4062003

1824 Written Statement of Caroline Leonard pp2-4 WITN3449100. She highlights that delivering palliative care well is not necessarily easy: “*I am advised Palliative care colleagues find it challenging to encourage other health care professionals to parallel plan for active treatment and palliative care in advanced liver disease. This challenge is partly due to the fluctuating course of the disease, with periods of recovery in between decompensation. The patients and their relatives often expect recovery ‘like the last time’ so it can be difficult conveying the need for advanced care planning and support.*”

the statutory and voluntary sectors, with a commitment to improving palliative and end of life care in England. To support the delivery plan, NHS England has funded the development of seven regional Palliative and End of Life Care Strategic Clinical Networks to meet local population needs, working to support the delivery of accessible, high-quality, sustainable personalised palliative and end of life care.<sup>1825</sup>

The Welsh government is working to develop active measures to identify and reduce evidenced inequities including diagnosis, mental health, dementia, age, geography, ethnicity, sexual and gender identity, and poverty. Work is also ongoing to review the funding of palliative and end of life care services across Wales. This review is encompassing the whole spectrum of end of life care services, including statutory and voluntary, specialist and generalist and the full age spectrum of children, young people, and adults.<sup>1826</sup>

## Commentary

As the above experiences demonstrate, the provision of palliative and end of life care to many of those infected by NHS blood and blood products has been inadequate, and a further way in which those infected and affected have been let down through a lack of access to good care. The positive experiences reported by some witnesses demonstrate a potential for good palliative care to make a positive difference at an otherwise distressing and traumatic time for a family.

The evidence of the experts in palliative care is that the importance of equitable access to high quality palliative care is underlined by the large number of people this affects. From the point of diagnosis of a life-limiting condition, appropriate palliative care should form a constituent part of patient management, based on a whole person approach that covers physical, psychological, social, and spiritual needs alongside pain and symptom control.

## Recombinant factor products

Blood products, as the name suggests, derive from human blood. As biological products, they will convey to a recipient any harmful matter which that blood contains – unless, that is, steps are taken to inactivate or remove what is harmful. However, that in turn necessitates being able to identify what is potentially harmful – if it cannot be sufficiently identified, it becomes difficult to remove or neutralise it. Though it is probable (as earlier chapters have demonstrated with infected blood and blood products) that so long as it is realised that there **may** be something harmful present in the blood the risk can be reduced by taking various protective measures, this is likely to reduce the risk rather than eliminate it. If however there is a synthetic equivalent to a blood product, which can be manufactured from a chemical rather than biological base, there will be little or no risk of any unanticipated disease being transmitted.

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<sup>1825</sup> Written Statement of James Sanderson paras 10-11, para 15 WITN7274001. James Sanderson is director of Community Health and Personalised Care at NHS England.

<sup>1826</sup> Written Statement of Professor Chris Jones para 3 WITN4065009

As a precaution against the transmission of blood-borne viruses, synthetic forms of treatment were developed. Recombinant factor products are one such product. They are manufactured using advanced recombinant DNA technology, instead of being derived from human plasma. They are now mainly used as a therapeutic treatment for individuals with bleeding disorders, in place of factor concentrates. Modern recombinant factor products are widely understood to be free of transfusion transmitted viruses, which is a fundamental advantage. It is for this reason that they are preferred to human plasma-derived factor products.

The first recombinant factor product was Factor 8. The recombinant Factor 8 within the product, which was the only active ingredient, constituted less than 1% by volume. The rest was albumin, which was an important constituent to stabilise the Factor 8 during freeze drying.<sup>1827</sup> Though albumin at the time, being a biological product, was of minimal risk the product was therefore not clear of all risk. Nonetheless, the risk was almost certainly less than that posed by plasma-derived concentrates.

There were difficulties for people with Haemophilia A gaining access to safer treatment in the form of recombinant Factor 8.

Recombinant Factor 8 was made available to UK health services in 1994. It was not cheap. Concerns about the lack of availability of recombinant Factor 8 due to cost started to arise during the next year. Professors Edward Tuddenham and Mike Laffan wrote in the *British Medical Journal* of 19 August 1995 that: “*Recombinant factor VIII is therefore the treatment of choice, given its freedom from viruses derived from plasma (adding albumin, which has an excellent safety record, does not alter this) ... The NHS struggles to pay for the high purity concentrate and is unlikely to pay for recombinant factor VIII. In the meantime, the spectre of unknown virus remains, and those who can pay for purity and safety are right to do so.*”<sup>1828</sup>

Recombinant cost some 70% more than high purity Factor 8.<sup>1829</sup> Nonetheless, on 2 November 1995 Dr Christine Lee and Dr Colvin wrote to the Secretary of State for Health, Stephen Dorrell, to argue the case for payment of the costs of treatment with recombinant Factor 8 concentrate. They reported that they had conducted a survey of UK haemophilia centre directors. To the best of their knowledge only two centres had secured the funds to purchase recombinant for some or all of their patients outside clinical trials.<sup>1830</sup>

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1827 Expert Witness Statement of Dr Trevor Barrowcliffe for an appeal by Baxter Healthcare before the Tax Tribunal 14 October 1996 pp3-4 DHSC0003540\_022

1828 Tuddenham and Laffan *Purified factor VIII: Theoretical advantages, but at a cost* British Medical Journal 19 August 1995 HSOC0006487

1829 Dr Hilary Pickles described the costs of treating a severe haemophiliac as “*astronomic*”. She went on to say that “*It is destined to become even worse, with the continuing rise in the costs of drugs (say with recombinant factor VIII at 43p/unit cf. BPL 8Y at 17p/unit).*” Letter from Dr Pickles to Dr Peter Doyle 20 June 1995 p1 DHSC0003986\_070. Dr Rejman wrote that he “*would agree that [sic] Dr Pickles that some fundholders might well not be happy about paying for haemophilia patients, some of whom may cost £250,000 per annum on a recurring basis. These are by far the most expensive patients being treated in the health service.*” Memo from Dr Rejman to Dr Doyle 28 June 1995 p1 DHSC0003986\_068

1830 Letter from Dr Lee and Dr Colvin to Stephen Dorrell 2 November 1995 DHSC0006173\_008

Matters were made more difficult when a decision was taken by HM Customs and Excise (“HMCE”) on 7 December 1995, with effect from 1 November, that recombinant Factor 8 could no longer be considered exempt from VAT, as had been the case, because they had realised it was not a biological product. It was a manufactured one. Thus, whereas high purity Factor 8, derived from human blood was VAT free, recombinant was not.<sup>1831</sup> It now cost at least double the price of high-purity plasma-derived Factor 8 concentrate.

On 21 December 1995, Dr Geoffrey Savidge, the clinical director of St Thomas’ Haemophilia Reference Centre and chair of the Recombinant Factor VIII Users’ Group, wrote to the Secretary of State for Health Stephen Dorrell stating that recombinant Factor 8 “*represents the safest product available to patients*” and sought reassurances that it would remain affordable.<sup>1832</sup>

The Haemophilia Society wrote to the Chancellor of the Exchequer, Kenneth Clarke, on 24 November 1995 asking him to reverse the VAT decision in the forthcoming budget. It described it as “*vital*” that this “*new, safer product should be available, at least to young children.*” The Society feared that hospital haemophilia centres which had not budgeted for the increase would not be able to afford it.<sup>1833</sup> A report in the *Daily Telegraph* of 25 November 1995 quoted Dr Winter as saying in respect of the VAT increase that “*No one doubts that recombinant Factor VIII is the best treatment. It is the safest and it is the future. I have already made the decision to give it to all my child patients. I now have to try to persuade my local purchasing authority to give me more money.*”<sup>1834</sup>

A draft reply was prepared for the Chancellor, Kenneth Clarke, in response to the letter of 21 December 1995 from Dr Savidge.<sup>1835</sup> The draft said that a number of measures were taken to ensure the safety of blood products generally, and that “*Although such steps are and will continue to be taken to minimise risk, these safeguards cannot guarantee absolutely the removal of that risk. Consequently the treatment of patients with recombinant Factor VIII, which contains human serum albumin as a stabiliser, is also not without risk*”.<sup>1836</sup>

1831 *Baxter Healthcare Ltd v Commissioners of Customs and Excise* Judgment 17 January 1997 p2 DHSC0002458\_009

1832 Letter from Dr Savidge to Stephen Dorrell 21 December 1995 DHSC0002458\_073. The Recombinant Factor VIII Users’ Group was a group of haemophilia centre directors prescribing recombinant Factor 8. Minutes of UK Haemophilia Centre Directors Organisation Executive Committee meeting 30 January 1996 p2 HCDO0000456

1833 Letter from Reverend Alan Tanner to Kenneth Clarke 24 November 1995 HSOC0008693

1834 The *Daily Telegraph* *VAT may hit care for haemophiliacs* 25 November 1995 HSOC0026885

1835 Letter from Dr Savidge to Kenneth Clarke 21 December 1995 DHSC0002458\_068

1836 Fax from HM Customs and Excise to Dr Rejman 23 January 1996 DHSC0002458\_070, Draft Letter from Kenneth Clarke to Dr Savidge 23 January 1996 DHSC0003540\_067. The full quotation is: “*It is generally accepted that treatment of patients with blood and medicinal products derived from human blood and plasma is not without risk. Safeguards are in place to minimise the risk of transmission of viruses. The safety of blood products depends on a number of factors which, taken together, reduce as far as possible the risk of viral infection. These include the screening of donors, the testing of donations, plasma pool testing and the ability of the manufacturing process to remove or inactivate viruses, and viral marker tests that can be undertaken on certain finished products. They relate to the manufacture of all blood products including Factor VIII. Although such steps are and will continue to be taken to minimise risk, these safeguards cannot guarantee absolutely the removal of that risk. Consequently the treatment of patients with recombinant Factor VIII, which contain human serum albumin as a stabiliser, is also not without risk.*” By way of comment, the logic of this is difficult to



In the Department of Health, draft briefing for an answer to a parliamentary question which arose in relation to the imposition of VAT on recombinant referred to the fact that “*Some practitioners prefer to use [recombinant], considering it safer than the product derived from human plasma. However, the Department considers that as albumin from human plasma remains an ingredient, albeit only as a carrier, some risk must remain, and that the natural product itself has a good safety record.*”<sup>1837</sup>

Within the year that followed before a decision by the tax tribunal (on an appeal by Baxter Healthcare Limited, which manufactured one of the two preparations of recombinant Factor 8 then licensed, against the 1995 decision that it should be subject to VAT) that an EC Directive indeed required the imposition of VAT on recombinant, there was much discussion in public whether recombinant product should be subject to VAT or not, whether it was a safer product to such an extent that extra expense should be incurred in order to provide it generally, and whether indeed it was the product of choice for clinicians. The government position by November 1996 was as set out then by John Horam, the Parliamentary Under-Secretary for Health. Baxter Healthcare Limited had approached the Minister, and were plainly keen that VAT should not be imposed. They were concerned that it placed sales of their recombinant product at a disadvantage. In reply, John Horam wrote as follows:

*“As I have explained to the Haemophilia Society, the Department’s aim is to ensure that the best health care is obtained for the resources available. We believe that aim is best achieved when decisions on appropriate treatments are made locally, taking account of the patient’s individual needs, the alternative treatments available and the availability of resources. Haemophiliacs are accordingly in no different position with regard to recombinant Factor VIII than that of any other patient where alternative treatments are available. Health care providers will need to be assured that demonstrable benefits will be achieved if extra costs are to be spent on one group of patients with correspondingly less available for others. In making that decision in the case in question, the Health Authority will no doubt take into account the fact that since the introduction of the viral inactivation*

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follow. The word “*consequently*” is out of place. This is near identical to a response sent by Dr Metters to Dr Lee on 25 May 1995. Letter from Dr Metters to Dr Lee 25 May 1995 BART0000633. Dr Metters makes the point that recombinant had a risk – that of being combined with albumin (which had for several years been used as a carrier medium for human vaccinations, and carried negligible risk) – though that is not a proper basis for comparing the risks of blood products on the one hand and recombinant on the other. The origin of this point appears to be a letter drafted by Dr Rejman in December 1994: “*there is no evidence that recombinant Factor VIII is any safer than plasma derived Factor VIII at the present time. You will be aware that recombinant Factor VIII contains plasma derived albumin as a carrier.*” Memo from Dr Rejman to D Jeffery 14 December 1994 p2 WITN4486067, Written Statement of Dr Andrzej Rejman para 78.10 WITN4486040. The Inquiry does not have a copy of the letter that Kenneth Clarke sent but it prompted a response from Dr Savidge: “*I was interested to read your comments concerning the comparative safety of the recombinant product, but unfortunately I cannot agree.*” Letter from Dr Savidge to Kenneth Clarke 1 April 1996 p1 DHSC0003540\_049

1837 Draft parliamentary answer on Factor VIII products and assessment for VAT purposes p1 DHSC0002458\_064. This makes the point the draft letter above attempted to convey, but more clearly does not seek to equate the risks. However, Dr Rejman was later to observe in an internal memo that “*You will recall that in summary the Department feels that there is **no justification for routine use of recombinant Factor VIII in patients with haemophilia***”. Emphasis added. Memo from Dr Rejman to Paul Pudlo 20 March 1996 p1 DHSC0003540\_055

*processes in 1985 plasma-derived Factor VIII has had a good safety record; furthermore all currently licensed forms of recombinant Factor VIII use human plasma derived albumin as a stabiliser and are not therefore wholly artificial and free from risk. I also understand that recombinant products themselves are not without side effects.”*<sup>1838</sup>

In short, the government did not intend to provide any extra money, nor to advise or require health authorities to fund recombinant. It was a matter for them whether they chose to do so.<sup>1839</sup>

So far as safety was concerned, Dr Savidge’s view, on behalf of the Recombinant Factor VIII Users’ Group was that the cheaper high purity plasma-derived Factor 8 was substantially contaminated by parvovirus B19. Recombinant Factor 8 was not.<sup>1840</sup>

Parvovirus was, he said, potentially pathogenic. Moreover, an unknown pathogenic virus could occur – he commented “*There is no absolute proof that this will occur, but then again there was no absolute proof in 1982-83 that HIV could be transmitted through blood products.*” He added that market trends in Europe, and North America showed that plasma derived Factor 8 was rapidly being phased out from clinical use in favour of recombinant.<sup>1841</sup>

In October 1996, the UKHCDO released guidelines in relation to the use of recombinant factor concentrates. These guidelines stated that “*recombinant factor VIII is now recommended treatment instead of plasma-derived concentrates.*” They also included guidance on the order of priority for the introduction of a treatment for which there was as yet limited availability: “*Recombinant factor VIII is the treatment of choice for all patients. If the introduction of recombinant factor VIII has to be prioritized then those who may benefit most should receive it first. Priority should therefore be given to those who have been least exposed to blood products in the past. These will most commonly be children.*”<sup>1842</sup>

The guidelines could not mandate health authorities to make finance available for the purchase of recombinant. The official position remained as John Horam had spelt it out. It is unsurprising, therefore, that concerns regarding its lack of availability continued to be raised.<sup>1843</sup>

In January 1997, the tax tribunal gave a detailed judgment when upholding HMCE in deciding that the sale of recombinant was liable to VAT. In the course of it, the tribunal

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1838 Letter from John Horam to Ian Thomas November 1996 DHSC0002458\_013

1839 The two principal reasons for delay in funding recombinant products in England appear to have been the costs, and the fact that plasma-based concentrates had by that stage a good safety record (albeit it was not as safe as recombinant).

1840 Letter from Dr Savidge to Kenneth Clarke 1 April 1996 p1 DHSC0003540\_049

1841 Letter from Dr Savidge to Kenneth Clarke 1 April 1996 p2 DHSC0003540\_049

1842 UKHCDO Executive Committee *Guidelines on therapeutic products to treat haemophilia and other hereditary coagulation disorders* Haemophilia 1997 pp10-11 BART0000875

1843 One typical concern was raised on 12 November 1996 when the parents of a child with haemophilia wrote to the Herefordshire Health Authority to complain about the lack of recombinant Factor 8, even though the use of the product had been deemed “*appropriate on clinical grounds*” by the treating clinician. Letter from Anon to Dr P Brooks 12 November 1996 HSOC0017402\_009

recorded findings of fact that recombinant was “*now considered as the treatment of choice by most clinicians and by the Haemophilia Society.*”<sup>1844</sup> If there had been doubts about this before, they were now objectively rejected. The tribunal also noted that recombinant had the advantages over blood-derived factor concentrate of being available in an unlimited supply, being a renewable source, and having freedom from blood-borne viral contamination. By comparison, purified plasma derived Factor 8 “*despite viral inactivation procedures, might contain low levels of viral contamination.*”<sup>1845</sup>

A Haemophilia Society Board of Trustees’ meeting in February 1997 recorded the unequal availability of recombinant Factor 8 across the UK: “*Some centres in the South have provided their children with recombinant, also Oxford and the Scottish Office. Others in the North and the Midlands have been unable to get funding from the Health Authorities.*”<sup>1846</sup>

On 3 March 1997, the chair of the Haemophilia Society wrote a letter to Stephen Dorrell. The letter reiterated the uneven availability of recombinant Factor 8 across the UK, including the “*very patchy*” availability for children. It also explained that the inequity existed “*because the decision on whether a child is offered recombinant is not made by the haemophilia clinician but rather by the Health Authority*”. The funding arrangements were, therefore, causing a geographical inequity of availability of recombinant Factor 8, as some health authorities were funding the provision of the treatment and others were not.<sup>1847</sup>

The letter also highlighted a problem at Manchester Children’s Hospital, where it said the consultant haematologist made the clinical decision to put a number of children on recombinant Factor 8, but the directors of public health in the area recommended that it should not be funded. Each individual health authority in the area subsequently met, and most decided to refuse funding for any use of recombinant Factor 8, even for newly diagnosed children. The hospital Trust then decided that if the health authorities would not guarantee the funding of recombinant, the children would have to revert to a plasma derived product: “*The clinical decision of the consultant and the wishes of the parents have been overruled by the Health Authorities. The parents of these boys are determined that they do not go back to a plasma derived product and are trying to make their supply of recombinant factor VIII last by not treating minor bleeds and curtailing the everyday activities of the boys to try and prevent bleeding.*” It pointed to the fact that in Scotland funding had been provided for the current financial year and was to be increased for the next, and called for a similar arrangement for the rest of the UK.<sup>1848</sup>

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1844 *Baxter Healthcare Ltd v Commissioners of Customs and Excise* Judgment 17 January 1997 para 17 DHSC0002458\_009. These were not findings essential to the decision. However, they do reflect an objective third party view of the evidence at the time.

1845 *Baxter Healthcare Ltd v Commissioners of Customs and Excise* Judgment 17 January 1997 para 17 DHSC0002458\_009

1846 Minutes of Haemophilia Society Board of Trustees meeting 13 February 1997 p3 HSOC0029689\_010

1847 Letter from Reverend Tanner to Stephen Dorrell 3 March 1997 p1 DHSC0004290\_087

1848 Letter from Reverend Tanner to Stephen Dorrell 3 March 1997 DHSC0004290\_087

The Society called for central funding to enable recombinant Factor 8 to be initially offered to two priority groups: “*previously untreated patients and those who are currently free from viral infection*”, which they considered would cover most children.<sup>1849</sup>

Whereas that letter reflected a view of the position in Manchester, following representations made by Haemophilia North, a panel established by Newcastle upon Tyne Hospitals NHS Trust recommended to the Board that “*it support the universal availability of recombinant Factor VIII. This recommendation should be conveyed to Health Authorities for funding*”.<sup>1850</sup>

On 12 March 1997, Graham Barker of the Haemophilia Society wrote a letter to Alf Morris MP indicating that some health authorities were refusing to pay the additional costs associated with recombinant Factor 8.<sup>1851</sup> Also in March 1997, Graham Barker wrote a letter to Liz Lynne MP. The letter drew attention to the Government’s reluctance to adopt the UKHCDO guidelines as well as highlighting the difference in approach in Scotland where all children with Haemophilia A had been transferred to recombinant treatment plans, by 1997.<sup>1852</sup>

During this period, the response of the Government remained as John Horam had set out earlier. The approach had been repeated – for instance, in April 1997 the Department of Health maintained in their response to campaigners that “*it is for clinicians to decide whether to use plasma-based factor VIII or recombinant factor VIII*.”<sup>1853</sup>

In August 1997, Dr (later Professor) Christopher Ludlam, chairman of the UKHCDO, wrote to Frank Dobson, who was now Secretary of State for Health. In his letter, Dr Ludlam raised his concerns about the inequality of haemophilia care across the UK, “*particularly as manifested by the very uneven availability of recombinant factor VIII*.”<sup>1854</sup> In September 1997 at a meeting between the Haemophilia Society and Department of Health, further concerns were raised that access to recombinant Factor 8 was not equal.<sup>1855</sup>

Due to the inequity of availability of recombinant factor concentrates, patient groups and organisations campaigned for the universal availability of the product for all Haemophilia patients. Jan Wallace describes her involvement in Haemophilia Wales’ campaign in 1997 to “*ensure all haemophiliacs in Wales received the safest treatment known as Recombinant*”, and how the “*Health Authorities were dragging their feet in providing funding for the safer treatment*”, despite this being the treatment of choice of the haemophilia centre director in Cardiff.<sup>1856</sup> Julie Morgan, MP for Cardiff North after the 1997 election, was approached by a number of constituents who were concerned about obtaining it, and she too campaigned

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1849 Letter from Reverend Tanner to Stephen Dorrell 3 March 1997 p2 DHSC0004290\_087

1850 Newcastle upon Tyne Hospitals NHS Trust *Position Statement on the Use of Recombinant Factor VIII* 22 February 2001 p1 DHSC0004285\_037

1851 Letter from Graham Barker to Alf Morris 12 March 1997 HSOC0012615\_012

1852 Letter from Graham Barker to Liz Lynne 14 March 1997 HSOC0017985\_018

1853 Letter from M Harvey to Jan Wallace 29 April 1997 p1 HSOC0017795\_010

1854 Letter from Dr Ludlam to Frank Dobson 29 August 1997 p1 DHSC0004290\_057

1855 Note of Haemophilia Society, Manor House Group and Department of Health meeting 10 September 1997 DHSC0046925\_074

1856 Written Statement of Jan Wallace pp5-6 WITN2688001

for its introduction. Professor Peter Collins, as director of the Cardiff Haemophilia Centre, made it a priority to advocate for its use.<sup>1857</sup> It became available, as a result, “*a year before England.*”<sup>1858</sup> Gareth Lewis, chair of the South Wales Haemophilia Group (which successfully campaigned) was able to point to what he described in 2001 as having been a “*major and unique achievement in the world of haemophilia care. The Haemophilia Centre at U.H.W. [University Hospital of Wales] is the only one in Europe possibly the world that can offer recombinant treatment to all its patients regardless of age and viral status. This would not have happened without the South Wales Haemophilia Group.*”<sup>1859</sup>

The concerns about one route of transmission of vCJD being blood-borne led to a decision in 1998 to introduce leucodepletion of blood (removal of the white cell component).<sup>1860</sup> It became clear that plasma or blood could transmit the defective prion which caused vCJD. It was that which led inexorably to recombinant therapy being generally adopted, and plasma-derived blood products thereafter being little used. The process may have been inexorable, but (although there was much in the general response of government to vCJD in blood to be admired by comparison with its response to AIDS in blood) it was also too slow.

It was not until 26 February 1998 that Frank Dobson announced that all health authorities were to make recombinant products available to children under 16 and previously untreated patients.<sup>1861</sup> Having authorised this, the Department for Health did not concede that a clinical case had yet been made in favour of recombinant products, but viewed the decision as made on humanitarian grounds.<sup>1862</sup> However, owing to the possible risk of transmission of blood-borne diseases, in particular vCJD, the decision was made to transfer these groups of patients to recombinant Factor 8.

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1857 “*One of the first priorities I had when starting in Cardiff was to advocate for universal access to recombinant coagulation factor concentrates ... This was achieved through engagement with the directors of Public Health and NHS Finance throughout Wales. In 1997, it was agreed that all people in Wales with haemophilia A should be switched to recombinant factor VIII from plasma-derived factor VIII. The switch to recombinant factor VIII took place over the next two years and Wales became the first country in the world with a policy of offering recombinant factor VIII to all people with haemophilia A.*” Written Statement of Professor Peter Collins para 46 WITN4029001

1858 Written Statement of Julie Morgan pp1-2 WITN2438001

1859 South Wales Haemophilia Group Information Pack February 2000 p6 WITN2412010, Written Statement of Beverley Tumelty p3 WITN2412008. Professor Peter Collins, who became the Cardiff haemophilia centre director in September 1996, said that it was agreed in 1997 that people with Haemophilia A in Wales should all be switched to recombinant Factor 8 and this took place over the next two years, with Wales becoming the first country in the world with a policy of offering recombinant Factor 8 to all people with Haemophilia A. Written Statement of Professor Peter Collins para 46 WITN4029001

1860 See the chapter on vCJD.

1861 Department of Health Press Release *Further Precautionary Measures on Blood Products Announced* 26 February 1998 p2 BART0002231

1862 Written Statement of Charles Lister para 4.3 WITN4505002, Memo from Dr Graham Winyard and Dr Metters to Baroness Jay 5 February 1998 p4 CABO0000014\_017. Professor Calman summarised the position in his written statement as follows: “*The decision in early 1998 to provide central funds to make recombinant products more widely available was driven not by a change in the science nor by a change in the Department’s understanding of the respective merits of plasma derived and recombinant products, but because of the entirely understandable fear felt by haemophilia patients and their carers in the face of the unknown but theoretical risk of vCJD and against a background of infection with blood borne viruses.*” Written Statement of Professor Sir Kenneth Calman para 72.3 WITN3430001

After this announcement, Carol Grayson wrote to Frank Dobson to enquire about plans to roll out recombinant to all patients, but was told in reply that “*there are no plans to arrange this centrally*” and that “*the Department of Health does not accept that the clinical case has been made for the general use of the recombinant product*”.<sup>1863</sup>

Patients and relatives also expressed concerns about the lack of clarity in the Department of Health’s policy for patients once they passed the age of 16. On 13 March 1998 one man wrote to Tony Blair expressing his concern that his son’s haemophilia treatment might revert to human-derived plasma after he reached the age threshold, as well as expressing further concerns about the affordability of recombinant Factor 8.<sup>1864</sup>

Subsequently, there was a Health Services Circular (HSC 1998/999) published on 17 March 1998. This document promulgated the announcement that central funding would be provided to health authorities in order to provide recombinant Factor 8 to new patients as well as patients under the age of 16. In addition, the circular included information about the future funding arrangements for these provisions.<sup>1865</sup>

On 21 August 1998, the Department of Health published a further Health Services Circular (HSC 1998/147). This document considered specific arrangements for health authorities to submit claims for additional funding to provide recombinant Factor 8.<sup>1866</sup>

The decision to fund recombinant Factor 8 for patients under the age of 16 as well as previously untreated patients had stemmed from the reality that these groups of patients were less likely to have been exposed to blood-borne viruses as compared to older patients with haemophilia. Patients who were outside these groups might still be treated with recombinant Factor 8, but this was a decision for the treating clinician as to whether they felt it was the best treatment option. It would then, as was the case before the Department of Health announcements, be left to the discretion of the health authority as to whether to provide sufficient funding.<sup>1867</sup>

The inequitable availability of recombinant Factor 8 caused significant anger and indignation among the Haemophilia A patient community as well as their relatives. Understandably, there was frustration because some patients were able to access recombinant Factor 8 whereas others were denied it as a treatment option.

In May 2001, the Haemophilia Society led a national campaign for the universal availability of recombinant Factor 8. The society encouraged individuals to write to their local MPs or

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1863 Letter from Tom McHugh to Carol Grayson 30 April 1998 WITN1055033

1864 Letter from Anon to Tony Blair 13 March 1998 DHSC0040895\_004

1865 NHS Executive Health Service Circular – Provision of Recombinant Factor VIII for new patients and children under the age of 16 17 March 1998 HCDO0000133\_021

1866 NHS Executive Health Service Circular – Provision of Recombinant Factor VIII for new patients and children under the age of 16: Claims for additional funding 21 August 1998 DHSC0006258\_050

1867 Written Statement of Charles Lister para 4.3 WITN4505002. At the November 1998 meeting of the UKHCDO Executive Committee Dr Ludlam said that Charles Lister had “*again informally indicated that funding for [Factor 8] should continue beyond the 16th birthday.*” Minutes of UKHCDO Executive Committee meeting 13 November 1998 p2 HCDO0000468

government officials by using a template letter which outlined the importance of funding recombinant Factor 8 for all Haemophilia A patients. The letter states that *“treatment by postcode is unfair and distressing to the haemophilia community.”*<sup>1868</sup>

Bruce Norval (in Scotland) described writing to the Secretary of State *“to try and make sure that kids got on to recombinant products as early as possible”*.<sup>1869</sup>

One man describes how the Birchgrove campaign group was *“not afraid to shock or rock the boat ... at the time when recombinant was being introduced, a number of members went on treatment strikes until recombinant was provided for all haemophiliacs.”*<sup>1870</sup>

Pete Longstaff refused human derived Factor 8 products in a treatment strike which lasted until his death.<sup>1871</sup>

Recombinant Factor 9 was licensed in 1999 and the funding arrangements in England mirrored those for Factor 8.<sup>1872</sup> In a letter dated 30 March 2005, he and his wife, Carol, noted that he had first requested recombinant in 1995 and been turned down in writing in March 1996: *“Peter and other haemophiliacs were repeatedly exposed to vCJD after that period and this exposure to vCJD could have been avoided in many cases.”*<sup>1873</sup>

It took until the end of 2000 before Scotland and Northern Ireland had confirmed that all haemophilia patients would be placed on recombinant treatment,<sup>1874</sup> although Wales had made that decision for Factor 8 in 1997.<sup>1875</sup>

In Scotland, the aim was to achieve universal provision of recombinant Factor 8 and 9 by April 2001 and by around 2002 all patients were in fact being treated.<sup>1876</sup>

By June 2003, it had been confirmed that in Northern Ireland recombinant Factor 8 would be funded for all patients.<sup>1877</sup>

In England, things happened more slowly. Charles Lister testified that in January 2001, ministers in England accepted his recommendation for recombinant to be made available for all adult haemophilia patients on a phased basis over a 4-5 year period starting in 2002-03, but there were issues about the availability of funding, which were not resolved until February 2003.<sup>1878</sup> As at 29 June 2003, individuals were still experiencing issues with

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1868 Haemophilia Society *The Campaign for Justice for people infected by contaminated blood products* 2001 p8 SCGV0000182\_102

1869 Written Statement of Bruce Norval para 36 WITN2235001

1870 Written Statement of ANON para 22 WITN1387015

1871 Written Statement of Carol Grayson para 282 WITN1055004

1872 Memo from Mike McGovern to Sheila Adam 4 January 1999 WITN4505216

1873 Letter from Carol and Peter Longstaff to Sister Julie Voles 30 March 2005 p1 WITN1055120

1874 Written Statement of Charles Lister para 4.4 WITN4505002

1875 Written Statement of Professor Peter Collins para 46 WITN4029001

1876 Email from Charles Lister to Nick Raisen 4 January 2001 p1 WITN4505247, Written Statement of Professor Philip Cachia para 67.3 WITN4028001

1877 Written Statement of Dr Julia Anderson para 10.11 WITN4027001

1878 Written Statement of Charles Lister para 4.6 WITN4505002. Charles Lister also explained that there was insufficient product on the market to meet the needs of the NHS immediately, and that additional

equal access to recombinant Factor 8 as a result of funding<sup>1879</sup> and it was not until the financial year 2004/2005 that all patients with Haemophilia A, of whatever age, had access to recombinant Factor 8.<sup>1880</sup>

An additional issue experienced by those seeking access to recombinant Factor 8 was the issue of insufficient supply. Between 2000 and 2002, there was a global shortage of recombinant products, due to the suspension of deliveries of Hexigate and Kogenate (Factor 8 products). The shortage had a substantial impact on the clinical availability of recombinant Factor 8 products in the UK. In Scotland, the shortage led to the treatment of older patients being transferred back to plasma-derived factor concentrates. In England and Northern Ireland, where the shortage was more extreme, the treatments of both children and older patients were, however, transferred to plasma-derived products.<sup>1881</sup>

The UKHCDO is still pushing for access to recombinant for all since recombinant von Willebrand Factor is not yet licensed for children.<sup>1882</sup> Children in Wales, though, can receive it off-label for on-demand treatment of non-surgical and surgical bleeding episodes and this is also possible in Scotland but has not been done in Northern Ireland.<sup>1883</sup> NHS England funds off-label usage for children after puberty but not younger.<sup>1884</sup>

## Commentary

For two reasons, recombinant factor product was desirable for treatment of people with haemophilia. First, many of those who were alive before 1992, and were still alive, had suffered infection with HIV, and more (possibly almost all) had suffered with Hepatitis C. They would have seen many of their friends die, often painfully, having in addition had to face indignities and stigma. They knew their families and close friends had been significantly affected in almost every aspect of their lives. They knew that the cause of this was their being given blood products which were infected, and that when that began no medical expert knew precisely what the cause was and how to avoid it. They had been assured, falsely as it turned out, that the products were relatively safe, that there was nothing to be worried about, that they should go on taking the treatment. After 1996, it may have seemed to be on the cusp of happening again as concern about vCJD took hold – and by the time the notification to them that they may be at heightened risk of this disease too being transmitted to them, it may have seemed that this nightmare was all happening again. In each case, the

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funding had to be obtained from the Treasury. Written Statement of Charles Lister para 4.5, paras 4.7-4.8 WITN4505002

1879 Letter from Colette Wintle to Lord Timothy Clement-Jones 29 July 2003 p1 WITN1056055

1880 Written Statement of Dr Paul Giangrande para 97.1 WITN3311003

1881 Letter from Professor Ludlam, Dr L Horn and Dr A Thomas to haemophilia patients 5 June 2001 pp4-6 SCGV0000182\_102

1882 Written Statement of Professor Pratima Chowdary WITN3826031

1883 Written Statement of Judith Paget WITN5712011, Written Statement of Caroline Lamb WITN7458050, Written Statement of Cathy Harrison WITN7744001. In Northern Ireland, access to recombinant blood products for children with von Willebrand disorder is available in exceptional cases through the Individual Funding Request (“IFR”) route, however to date no IFR has been made.

1884 NHS England is in the early stages of considering the possibility of off-label usage for patients under 12. Written Statement of Daniel Eve paras 4-6 WITN7745001



cause had started with blood products being of human origin, so that what one person had could be passed to another. They – and parents concerned about the treatment available for the next generation – had every right to be seriously worried.

Worry and anxiety are in themselves not necessarily sufficient reasons for providing funding where it might not otherwise be provided, where it involves paying more for treatment than would otherwise be the case: but the group as a whole had been harmed by treatment from the very body which was now threatening to expose them to harm again, as they reasonably saw it, and they were (generally) in no position to fund more acceptable treatment for themselves.

Second, the predominant concern should be the safety of the patient. It is right to acknowledge that using money to fund one treatment may deprive another patient with a different condition from having their treatment funded, such that an overall view of safety has to be taken. However, recombinant was undoubtedly safer (indeed, though recognition of this was somewhat grudging when it was first licensed, that seems over time to have been fully recognised); such that even before risks of vCJD being transmitted by blood were properly recognised there was a powerful argument for recombinant treatment being funded for all, and once those risks were recognised it became unanswerable. It is to be noted that most if not all haemophilia clinicians supported its use; patient groups advocated it; many health authorities saw the force of the arguments in its favour; and Wales led the way in 1997.

When coupled with a recognition of the very particular claims of the patient group concerned, recombinant treatment for all was not only desirable, but should have been funded earlier than it was across the whole of the UK – though Wales is excluded from this comment for reasons which are obvious from the chronology. They became first in the world to provide it.

## 6.13 Inquests, Fatal Accident Inquiries and Death Certificates

This chapter examines how the systems for certifying and investigating death developed, and how the stigma of vCJD, HIV, Hepatitis B, and Hepatitis C influenced the decisions made. It documents individuals' experiences and illustrates deficiencies in central guidance and training to doctors.

### Key Dates

**1836** establishment of death registration system in England and Wales.

**1855** requirement to register deaths in Scotland.

**1864** requirement to register deaths in Ireland.

**1874** requirement in England and Wales to record the cause of death.

**1965** the Brodrick Committee is established to examine death certification and coronial systems; reports in **1971**.

**1968** Registration of Births, Deaths and Marriages Regulations.

**1986** British Medical Association publishes report *Deaths in the Community*.

**13 May 1987** Minister for Health, Tony Newton, acknowledges sensitivities in reporting AIDS and HIV on death certificates.

**June 2003** Home Office publishes: *Death Certification and Investigation in England, Wales and Northern Ireland: The Report of a Fundamental Review 2003*.

**July 2003** Shipman Inquiry third report *Death Certification and the Investigation of Deaths by Coroners*.

**2006** Select Committee report *Reform of the coroners' system and death certification*.

**2009** Cullen Review of Fatal Accident Inquiry legislation in Scotland.

**2011** Certification of Death (Scotland) Act.

**2013** wide-scale reforms to the coronial system in England and Wales are implemented including the creation of the role of Chief Coroner.

**2015** guidance on *Reporting Deaths to the Procurator Fiscal issued in Scotland*.

**2016** Fatal Accidents and Sudden Deaths etc (Scotland) Act.

**September 2018** *Guidance for Doctors completing medical certificate cause of death and its quality assurance* issued in Scotland.

**2022** *Guidelines for Death Certification* issued in Northern Ireland.

**September 2024** new statutory medical examiner system coming into force in England and Wales.

### Abbreviations

**BMA** British Medical Association

**FAI** Fatal Accidents Inquiries

**MCCD** medical certificate of cause of death

**OPCS** Office of Population Censuses and Surveys

**vCJD** variant Creutzfeldt-Jakob disease

Certifying death which is related to infection with HIV, Hepatitis B, Hepatitis C or a combination of these, or variant Creutzfeldt-Jakob disease (“vCJD”) and in particular identifying the cause on death certificates has led to concerns for many participants in the Inquiry. These concerns are explored in the second half of the chapter. The first half of the chapter explains how the systems for certifying and investigating deaths have developed.

## Certification and investigation: the context

When a person’s death is registered, the cause of their death is recorded. For some family members this has been of particular importance because the certificate is a permanent record of what happened to their loved one. Far too often, the death certificate has not accurately recorded the cause of death. Sometimes a doctor took the decision paternalistically, without asking the family, that it was better for the family that (for example) HIV was not recorded on the death certificate for fear of the stigma that the family members would face. Some families were grateful for this protection. Other families specifically requested that the doctor should do this, recording for example that the person died of pneumocystis pneumonia instead of HIV. Others have felt equally strongly that this was wrong and that they should have been given the choice about whether or not the complete cause of death was given or not. Still others were unaware that a cause of death that was put on the death certificate was opaque and only latterly have come to understand that it does not represent the full story.

The right to life is of fundamental importance. When a person dies, it is important to know if this has been interfered with, either by the state or in a way which the state could put right. It is important not just for their family and friends to know why the death has occurred, but for society more generally both to know that it has happened and what the cause was – especially because there may be lessons to be learned from one death which will help prevent other deaths occurring in a similar manner.

A Fundamental Review of Death Certification and Investigation in England, Wales and Northern Ireland took place in 2003, in the wake of the Shipman scandal, the deaths caused by Beverley Allitt, and the deaths of “heart babies” at Bristol Royal Infirmary.<sup>1885</sup>

It asked the critical question: what is death certification, and the coroner’s jurisdiction, for?

The answer it gave was to identify seven functional objectives. These were separated into two heads – “*Death Verification and Certification*” and “*Death Investigation through the Coroner Service*”. The purposes of certification were identified as being:

- “1. to confirm formally that death has occurred;
2. to certify to the best of the certifier’s knowledge and belief that the death has occurred from natural disease and that there are no suspicious or other circumstances requiring investigation;

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<sup>1885</sup> *Death Certification and Investigation in England, Wales and Northern Ireland: The Report of a Fundamental Review 2003* June 2003 RLIT0001915. The review was chaired by Tom Luce, formerly head of social care policy at the Department of Health.

3. *to give medical causes of the death which to the best of the certifier’s knowledge and belief explain the death, are suitable for inclusion in the permanent record of the death, and enable the family to understand why it occurred;*
4. *to provide information on the cause of death for inclusion in the national mortality statistics which, along with other sources of information on the causes of death and disease, contribute to the maintenance and improvement of public health and safety”*.<sup>1886</sup>

The purpose of investigation by a coroner was identified as being:

- “5. *to satisfy the public that there is an independent and professional process for scrutinising deaths of uncertain cause or circumstances, and for investigating all deaths of people detained by the state or dying at the hands of state agents, or otherwise in situations of special vulnerability or where special vigilance is required;*
6. *to help families understand the causes and circumstances of the death of the family member in cases of significant uncertainty which cannot be resolved through other processes;*
7. *to contribute along with other public services and agencies to the avoidance of preventable deaths.”*<sup>1887</sup>

These purposes are a useful starting point for this chapter. They were set out in 2003, together with the service values which the review saw as desirable.<sup>1888</sup> However, death certification has a much longer history.

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1886 *Death Certification and Investigation in England, Wales and Northern Ireland: The Report of a Fundamental Review 2003* June 2003 p32 RLIT0001915

1887 *Death Certification and Investigation in England, Wales and Northern Ireland: The Report of a Fundamental Review 2003* June 2003 p32 RLIT0001915

1888 These were designed for England, Wales and Northern Ireland. The service values of greatest relevance to the Inquiry are:

- “1. *meet public safety, public health, public confidence and human rights requirements for the protection of life throughout all sections of the community without discrimination or favour, with full independence and proper accountability;*
2. *ensure that information on preventable deaths is made fully available and has proper influence;*
3. *so far as is consistent with 1 and 2 respect individual, community and family wishes, feelings and expectations, including community and family preferences, traditions and religious requirements relating to mourning and the disposal of the dead; and respect family and individual privacy;*
4. *allow participation by families and bereaved people in the processes of certifying and where necessary investigating deaths, treating them sensitively and with dignity, helping them find further help where this is necessary, and meeting their concerns and uncertainties as promptly and effectively as possible;*
5. *provide a seamless service when certifying or investigating deaths with a single point of access for families, thus avoiding unnecessary confusion and distress.”*

*Death Certification and Investigation in England, Wales and Northern Ireland: The Report of a Fundamental Review 2003* June 2003 p33 RLIT0001915

## Historical context of death registration

A system of death registration was established in 1836 in England and Wales.<sup>1889</sup> In Scotland it was compulsory to register deaths including the cause of death from 1855 and in Ireland from 1864.<sup>1890</sup> It was however not until 1874 that it was required that the death **and cause of death** of every person dying in England and Wales be recorded by the registrar.<sup>1891</sup> There was a further statute in 1926 which allowed the coroner to register a death.<sup>1892</sup>

Concerns about the accuracy of the information contained in death certificates in England and Wales were raised as early as 1964 by the British Medical Association (“BMA”),<sup>1893</sup> and in 1965 a Home Office Departmental Committee of Enquiry was established (“the Brodrick Committee”) to examine the death certification and coronial systems.

Before the Committee could report its findings, the Registration of Births, Deaths and Marriages Regulations 1968 were passed. These specified the forms that had to be used and the details that were required for death registration. A report to the coroner was required where there was a gap of more than 14 days between the last doctor’s attendance and the death.<sup>1894</sup>

The Brodrick Committee made a variety of recommendations. They included that the certifying doctor:

- (a) must be *“a fully registered medical practitioner ... and have attended the deceased person at least once during the seven days preceding death”*
- (b) should be *“obliged to inspect the body of the deceased person ... and EITHER send a certificate of the fact and cause of death to the registrar of deaths, OR report the death to the coroner”*
- (c) *“should issue a certificate of the fact and cause of death only if:*
  - (i) *he is confident on reasonable grounds that he can certify the medical cause of death with accuracy and precision;*
  - (ii) *there are no grounds for supposing that the death was due to or contributed to by any employment followed at any time by the deceased, any drug, medicine or poison or any violent or unnatural cause”*<sup>1895</sup>

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1889 Births and Deaths Registration Act 1836.

1890 Registration of Births, Deaths and Marriages (Scotland) Act 1854 Schedule B p9 RLIT0002327, Registration of Births and Deaths (Ireland) Act 1863 Form B p10 RLIT0002328

1891 That information had to be provided to the registrar by the registered medical practitioner who had seen the person during their last illness. Births and Deaths Registration Act 1874 sections 9, 20(2), 51 RLIT0002323

1892 Births and Deaths Registration Act 1926 RLIT0002322

1893 BMA *Deaths in the Community* 1964 pp6-7 BMAL0000097. See also BMA *Deaths in the Community* 1986 p4, pp9-10 BMAL0000096

1894 Registration of Births, Deaths and Marriages Regulations 1968 section 51(1)(c) RLIT0002321

1895 Home Office *Report of the Committee on Death Certification and Coroners* November 1971 p181 RLIT0001858

Despite the Brodrick Committee having made its recommendations in 1971, by 1982 the Registrar General noted that *“the main proposals ... about the medical certification of the cause of death have yet to be brought into effect.”*<sup>1896</sup>

He consulted with the medical profession and others about whether further legislative amendments were required. They were not in favour of the period in which a medical practitioner must have attended being shortened from 14 days to seven days.<sup>1897</sup>

As part of this consultation, the Private Practice Committee of the BMA wrote to the Registrar General noting that the Brodrick Committee recommendations had:

*“never been accepted by the medical profession, or indeed adequately discussed. You will know ... that the view of the profession is that some amendment to the death certificate is desirable, and we believe that this commends widespread support amongst all interested parties. From a statistical point of view, there is no doubt that the present death certificate yields inadequate, and often incorrect, information to your Department, and that this in turn has consequences for Public Health which are of more direct concern to the medical profession.”*<sup>1898</sup>

The BMA’s report in 1986 (*“Deaths in the Community”*) considered many aspects of the ways in which coroners worked, but said little about what might be done to improve the *“inadequate and often incorrect information”* (as its Private Practice Committee had labelled it) being supplied on a death certificate. It did however note that whereas in many countries simply the fact of death was recorded, in the UK it was the *“cause of death”*. Though in setting out a cause of death this made the fact of death self-evident, the BMA thought that where practitioners could not be sure of the cause of death they should certify the fact of death to the coroner. The Brodrick Committee had recommended this. The recommendation had not been acted on. The BMA thought it would be sensible to implement it.<sup>1899</sup>

On 16 March 1988, a meeting was held between the BMA and the Office of Population Censuses. At the meeting, it was again acknowledged that *“nothing had happened by way of implementation with regard to registration of deaths”* since the Brodrick report.<sup>1900</sup> It follows that a cause of death had to be given, even where the certifying practitioner was

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1896 Letter from A Thatcher to B Brideaux 25 February 1982 p1 HOME0000058\_100

1897 They also raised questions about whether the formulation of certifying the cause of death with *“accuracy and precision”* would result in more post mortems. A variety of views were expressed from a range of bodies including the BMA, the Royal College of Pathologists, the Royal College of Surgeons, the Royal College of Radiologists, the Royal College of Obstetricians and Gynaecologists, the Royal College of General Practitioners, the Coroners’ Society, the Association of Metropolitan Authorities, the Association of County Councils, and the Greater London Council. List of recipients from the medical profession HOME0000058\_101, Memo from G de Deney to Mr Mayhew and the Secretary of State 7 December 1982 HOME0000058\_011, Letter from A Thatcher to B Brideaux 25 February 1982 HOME0000058\_100, Views of medical bodies on death certification HOME0000058\_064

1898 Letter from Andrew Bosi to A Thatcher 26 May 1982 p1 HOME0000058\_080

1899 BMA *Deaths in the Community* 1986 p8 BMAL0000096

1900 Minutes of BMA and Office of Population Censuses and Surveys meeting 16 March 1988 pp1-2 HOME0000067\_010

unsure of it, and that the certification might be inaccurate (since a doctor might not be at all sure of what it was).

Then in 2001, the Home Office established a Fundamental Review of Death Certification and the Coroner Services in England, Wales and Northern Ireland, following public concerns after deaths caused by Harold Shipman, Beverley Allitt and at the Bristol Royal Infirmary. The Review reported in June 2003. The Review identified that the “*critical weaknesses*” of the death certification process included: the fragmentation of the system, which was concerned with individual deaths but not with patterns or trends; the absence of any oversight of the certification process to ensure that it was properly carried out; and the lack of clear participation rights for bereaved families, who were “*largely excluded from the death certification process*”.<sup>1901</sup> It made a number of recommendations “*to deal with defects that we have identified – to create a service that has consistent and known national standards, that safeguards the public but makes good service to bereaved families a major priority, that is equipped with modern duties and powers, proper professional leadership, and the range of legal, medical and investigative and human skills necessary for these purposes.*”<sup>1902</sup>

A public inquiry was held into the deaths caused by Dr Harold Shipman and issued its third report (“*Death Certification and the Investigation of Deaths by Coroners*”) just one month after the Fundamental Review, in July 2003. In her foreword, Dame Janet Smith wrote:

*“A sound system will advance medical science, through the better understanding of causes of death. It will assist in planning for the better use of the huge resources now expended on the National Health Service ... my investigations have satisfied me that the system is not working as well as it should. The evidence received by the Inquiry suggests that there is much dissatisfaction with the present arrangements. It is said that the existing system is fragmented, is not sufficiently professional, is applied to very variable standards in different parts of the country and does not meet the needs of the public, especially the bereaved. It is said that it does not satisfy the public interest in the discovery of the true causes of death in the population. It does not contribute, to the extent that it should, to the improvement of public health and safety.”*<sup>1903</sup>

Amongst other matters, Dame Janet Smith considered that the certification process should include the preparation of a brief summary of the deceased’s recent medical history and the chain of events leading to death. The forms she proposed for use contained a box in which the doctor could express an opinion as to the cause of death, but should do this “*only if the doctor is able to express an opinion with a high degree of confidence.*”<sup>1904</sup>

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1901 *Death Certification and Investigation in England, Wales and Northern Ireland: The Report of a Fundamental Review 2003* June 2003 pp24-25 RLIT0001915

1902 *Death Certification and Investigation in England, Wales and Northern Ireland: The Report of a Fundamental Review 2003* June 2003 p29 RLIT0001915

1903 *The Shipman Inquiry Third Report: Death Certification and the Investigation of Deaths by Coroners* July 2003 p7 RLIT0001826

1904 *The Shipman Inquiry Third Report: Death Certification and the Investigation of Deaths by Coroners* July 2003 pp512-513 RLIT0001826

A subsequent Select Committee report identified the main functions of death certification in these words: *“The death certification and investigation systems have essential roles, providing each person who dies with a last, posthumous, service from the State; they serve families and friends by clarifying the causes and circumstances of the death; and they contribute to the health and safety of the public as a whole by providing information on mortality and preventable risks to life.”*<sup>1905</sup> Both these functions are important to many participants in this Inquiry.

The Select Committee noted that both the Fundamental Review and the Shipman Inquiry had *“found the systems for the certification and investigation of deaths in England and Wales to be unfit for modern society.”*<sup>1906</sup> It assessed that coroners undertook their statutory function *“in a fragmented and localised system that has remained largely unchanged since the time of Queen Victoria”* with coroners *“amongst the greatest proponents of change.”*<sup>1907</sup> It was nonetheless able to conclude that the *“coronial system is appropriate for the purposes of modern society, subject to significant reforms.”*<sup>1908</sup>

In short, it was recognised that the system of death certification which had operated during the 1970s, 1980s and 1990s, was in need of *“significant”* (to use the Select Committee’s word) or *“radical”* (to use Dame Janet Smith’s term) reform.<sup>1909</sup> These decades are of particular interest to this Inquiry when it comes to recording the cause of death.

## Current position on death registration and certification

### England and Wales

The current legislative framework requires that: *“the death of every person dying in England or Wales and the cause thereof shall be registered by the registrar of births and deaths for the sub–district in which the death occurred by entering in a register kept for that sub–district such particulars concerning the death as may be prescribed.”*<sup>1910</sup>

Where there is no involvement of a coroner, a relative, or an administrator from the hospital, will register the death with the registrar. They will provide the registrar with certification of the cause of death, completed by a registered medical practitioner. The practitioner must sign the certificate *“stating to the best of his knowledge and belief the cause of death”*.<sup>1911</sup>

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1905 House of Commons Constitutional Affairs Committee *Reform of the coroners’ system and death certification* 1 August 2006 p10 RLIT0002270

1906 House of Commons Constitutional Affairs Committee *Reform of the coroners’ system and death certification* 1 August 2006 p7 RLIT0002270

1907 House of Commons Constitutional Affairs Committee *Reform of the coroners’ system and death certification* 1 August 2006 p12 RLIT0002270

1908 House of Commons Constitutional Affairs Committee *Reform of the coroners’ system and death certification* 1 August 2006 p15 RLIT0002270

1909 House of Commons Constitutional Affairs Committee *Reform of the coroners’ system and death certification* 1 August 2006 p15 RLIT0002270, The Shipman Inquiry *Third Report: Death Certification and the Investigation of Deaths by Coroners* July 2003 p8 RLIT0001826

1910 Births and Deaths Registration Act 1953 section 15 p19 RLIT0002269

1911 Births and Deaths Registration Act 1953 section 22(1) p22 RLIT0002269



The registrar will then formally register the death and issue a certificate of registration of death (the death certificate).<sup>1912</sup>

Guidance for completing a medical certificate of cause of death (“MCCD”) for clinicians in England and Wales states that:

*“doctors are expected to state the cause of death to the best of their knowledge and belief; they are not expected to be infallible ... You are asked to start with the immediate, direct cause of death on line I(a), then to go back through the sequence of events or conditions that led to death on subsequent lines, until you reach the one that started the fatal sequence. If the certificate has been completed properly, the condition on the lowest completed line of part I will have caused all of the conditions on the lines above it ... **From a public health point of view, preventing this first disease or injury will result in the greatest health gain.** Most routine mortality statistics are based on the underlying cause ... Remember that the underlying cause may be a longstanding, chronic disease or disorder that predisposed the patient to later fatal complications.”*<sup>1913</sup>

It explains that line I(a) in the MCCD should address the disease or condition leading directly to death; line I(b) should contain any other disease or condition, if any, leading to I(a), and line I(c) to any other disease or condition leading to I(b). Part II should include other significant conditions contributing to death but not related to the disease or condition causing it.<sup>1914</sup>

Changes are currently being made to the scheme of certification of deaths. In 2019 NHS England and NHS Wales started to implement medical examiner systems whereby all deaths are independently scrutinised by medical examiners if they are not referred to the coroner.<sup>1915</sup> This is intended to ensure that a review is undertaken into each death by a medical professional who is independent of the care provided to the deceased, allowing for (it is hoped) a more objective assessment and accurate recording of the cause of death.<sup>1916</sup> Regulations to give statutory footing to the medical examiner system were laid before Parliament in April 2024 and come into force in September 2024.

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1912 The Coroners and Justice Act 2009 provides for a system of death certification under which all deaths in England and Wales that do not require investigation by a coroner will be subject to scrutiny by independent medical examiners. These provisions of the Coroners and Justice Act 2009 had not been brought into force but the Medical Certificate Cause of Death Regulations 2025, the Medical Examiners (England) Regulations 2024, the National Medical Examiner (Additional Functions) Regulations 2024 and the Medical Examiners (Wales) Regulations 2024 were laid before Parliament on 15 April 2024 and will come into force on 9 September 2024. For further information see: House of Commons Library *Death Certification and Medical Examiners* 3 November 2021 p18 RLIT0001905

1913 Office for National Statistics and HM Passport Office *Guidance for Doctors Completing Medical Certificates of Cause of Death in England and Wales* 2022 pp4-5 WITN7591017. Emphasis in original.

1914 Office for National Statistics and HM Passport Office *Guidance for Doctors Completing Medical Certificates of Cause of Death in England and Wales* 2022 p5 WITN7591017

1915 A National Medical Examiner for the NHS was appointed in March 2019 and issued good practice guidelines in January 2020.

1916 House of Commons Library *Death Certification and Medical Examiners* 3 November 2021 pp25-28 RLIT0001905

## Scotland

For medical certificates of the cause of death in Scotland, the certifying practitioner should be *“The doctor with the most detailed knowledge of the circumstances of death”*.<sup>1917</sup> The doctor must state *“to the best of his knowledge and belief the cause of death and such other medical information”* as required.<sup>1918</sup> Any death which may be related to a suggestion of neglect, where there is an allegation or possibility of fault on the part of another person, body or organisation, or where it arises from a notifiable industrial or infectious disease where it poses an acute and serious risk to public health is to be reported to the procurator fiscal. So too must be deaths occurring under medical care, *“the circumstances of which are the subject of concern to, or complaint by, the nearest relatives of the deceased about the medical treatment given to the deceased with a suggestion that the medical treatment may have contributed to the death of the patient”* or *“the circumstances of which might indicate fault or neglect on the part of medical staff or where medical staff have concerns regarding the circumstances of death”*, or *“where, at any time, a death certificate has been issued and a complaint is later received by a doctor or by the Health Board, which suggests that an act or omission by medical staff caused or contributed to the death.”*<sup>1919</sup>

On 21 September 2018, the Chief Medical Officer (“CMO”) for Scotland and the Acting Registrar General and Keeper of the Records of Scotland circulated *“Guidance for Doctors completing medical certificate of cause of death and its quality assurance”* to doctors in Scotland. This guidance explains the changes made by the Certification of Death (Scotland) Act 2011, including the introduction of independent reviews intended to monitor the accuracy of death certification. The independent reviews involve a randomised selection of the medical certificates of cause of death being selected for review through the registration system and scrutiny by a medical reviewer. This is done by the Death Certification Review Service, which is run by Healthcare Improvement Scotland.<sup>1920</sup>

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1917 Crown Office and Procurator Fiscal Service *Reporting Deaths to the Procurator Fiscal: Information and Guidance for Medical Practitioners* 2015 p3 COPF0000107

1918 Registration of Births, Deaths and Marriages (Scotland) Act 1965 section 24 p27 RLIT0002261, as amended by the Certification of Death (Scotland) Act 2011 RLIT0002267

1919 Crown Office and Procurator Fiscal Service *Reporting Deaths to the Procurator Fiscal: Information and Guidance for Medical Practitioners* 2015 pp4-6 COPF0000107. These are set out under *“Categories of Death to be Reported”* under the sub-heading *“Natural cause of death”*. The category of deaths associated with medical care is set out in more detail:

*“Most deaths under medical care represent an unfortunate outcome where every reasonable care has been taken. However, some deaths associated with the provision of medical care may involve fault or negligence on the part of medical or paramedical staff and may give rise to questions of public safety and, in rare cases, may be associated with criminality.*

*Medical care includes surgical, anaesthetic, nursing or other care/treatment whether provided in a healthcare or non-healthcare setting.*

*The Procurator Fiscal may decide to instruct an independent expert in the relevant field to provide an opinion on the circumstances of the death. The expert may wish to discuss the circumstances of the death with the doctor(s) involved in the treatment of the deceased.*

*Similar principles should apply to any death in the course of dental treatment.”*

Crown Office and Procurator Fiscal Service *Reporting Deaths to the Procurator Fiscal: Information and Guidance for Medical Practitioners* 2015 pp9-10 COPF0000107

1920 Letter from the Scottish CMO to colleagues 21 September 2018 pp9-10 RLIT0001096, Certification of Death (Scotland) Act 2011 section 2 pp1-3 RLIT0002267

## Northern Ireland

In Northern Ireland, every death, the cause of the death and prescribed particulars must be registered by the registrar for the district where the body is found. Where a person dies “as a result of any natural illness for which he has been treated by a registered medical practitioner within twenty-eight days prior to the date of his death”, that medical practitioner shall sign a certificate stating “to the best of his knowledge and belief the cause of death”. In other circumstances the death must be reported to the coroner.<sup>1921</sup> Guidance issued by the Northern Ireland Department of Health explains that death certification serves social, legal and health functions, providing the family with an explanation of how and why their relative died, and providing the underlying cause of death which influences (amongst other matters) the design and evaluation of public health interventions and the assessment of the effectiveness of health services.<sup>1922</sup>

## Investigating deaths

Some deaths require more than registration: they need investigation. Inquests in England, Wales and Northern Ireland and Fatal Accident Inquiries (“FAIs”) in Scotland are essential in providing families with the opportunity to seek and hopefully obtain answers about what happened to their loved one, why it happened and how further deaths might be prevented in the future. For some of those who have lost loved ones to infections arising from blood products or blood transfusions, a failure to investigate their deaths has caused them to feel that there has at least been a lack of transparency, and in some cases a feeling that there has been a cover-up in investigating the reasons for their infections and deaths.

In Scotland, a procurator fiscal decides whether to hold a fatal accident investigation into those deaths of which he is informed under the provisions discussed above. If he decides that there should be, a sheriff carries out the inquiry.

In England and Wales the answer to when coroners are to be told of a death so that they may choose to investigate it is given in statutory regulations. The circumstances include those where a registered medical practitioner suspects that the person’s death was due to: “(a)(i) poisoning, including by an otherwise benign substance; (ii) exposure to or contact with a toxic substance; (iii) the use of a medicinal product ... (viii) the person undergoing a treatment or procedure of a medical or similar nature” or “(b) ... that the person’s death was unnatural but does not fall within any of the circumstances listed in sub-paragraph (a)”.<sup>1923</sup>

Guidance given as to these regulations makes clear what the words “due to” mean – “where there is reasonable cause to suspect that the death was due to (that is, more than

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1921 Births and Deaths Registration (Northern Ireland) Order 1976 sections 21, 25 RLIT0002320. Read together with: Coroners Act (Northern Ireland) 1959 WITN7589002

1922 Guidelines for Death Certification: Issuing a Medical Certificate of Cause of Death (MCCD) using the Northern Ireland Electronic Care Record (NIECR) 2022 p2 RLIT0002319

1923 The Notification of Deaths Regulations 2019 section 3 p2 RLIT0002308

*minimally, negligibly or trivially) caused or contributed to*” by any of the causes listed under the regulation.<sup>1924</sup>

In her third report of the Shipman Inquiry, Dame Janet Smith noted the questions to be determined when an inquest is held:

**“(1) The proceedings and evidence at an inquest shall be directed solely to ascertaining the following matters, namely –**

- (a) who the deceased was;**
- (b) how, when and where the deceased came by his death;**
- (c) the particulars for the time being required by the Registration Act to be registered concerning the death**

**(2) Neither the coroner nor the jury shall express any opinion on any other matters.”**<sup>1925</sup>

She commented: *“these provisions throw little light on why it is thought desirable to discover these facts”*.<sup>1926</sup>

After setting out various attempts that had previously been made to give some (less than comprehensive or satisfactory) answers to this critical question,<sup>1927</sup> she suggested that:

*“In my view, in the modern era, the purposes of the public inquest should be:*

- to conduct a public investigation into deaths which have or might have resulted from an unlawful act or unlawful acts*
- to inform interested bodies and the public at large about deaths which give rise to issues relating to public safety, public health and the prevention of avoidable death and injury*

1924 The guidance also says about deaths due to the use of a medicinal product: *“This applies to deaths due to either the deliberate or accidental intake or administration of medicinal products or any other drugs, or any complications arising from this. Examples of this include, but are not limited to: 1) Illicit, or recreational drugs. 2) Medical drugs, including but not limited to, prescribed or non-prescribed medication (e.g. a self-administered overdose or an excessive dose given either in error or deliberately).”* Ministry of Justice *Guidance for registered medical practitioners on the Notification of Deaths Regulations* March 2022 p4, p5 RLIT0002306

1925 Emphasis in original. The Shipman Inquiry *Third Report: Death Certification and the Investigation of Deaths by Coroners* July 2003 para 9.77 RLIT0001826. The legislation then in force in England and Wales was the Coroners Act 1988 RLIT0002273 and the Coroners Rules 1984 RLIT0002257 but the questions to be determined remain the same under the Coroners and Justice Act 2009 RLIT0002266.

1926 Emphasis in original. The Shipman Inquiry *Third Report: Death Certification and the Investigation of Deaths by Coroners* July 2003 para 9.78 RLIT0001826

1927 And apparently influenced by what Lord Justice Simon Brown had suggested in an earlier case (that there was a powerful case for holding an inquest *“whenever a wholly unexpected death, albeit from natural causes, results from some culpable human failure”*) concerning a death which occurred in hospital possibly as a result of hospital treatment. *“Possibly”* because that matter had not yet finally been determined by a court or inquest. *R v Inner London North Coroner, ex parte Touche* para 43 21 March 2001 RLIT0002307

- *to provide public scrutiny of those deaths that occur in circumstances in which there exists the possibility of an abuse of power.*<sup>1928</sup>

Inquests and FAls are (and were, throughout the period of central interest to the Inquiry) inquisitorial, investigative processes which seek to establish facts surrounding certain deaths. In contrast to litigation, inquests and FAls are not adversarial processes and the purpose is not to apportion blame.<sup>1929</sup> However, that is not to say that they are uncontentious: where, for instance, a family are seeking to know why their loved one died, the form of the verdict and the information revealed by the inquisitorial procedure may fuel further proceedings, either of a civil or sometimes criminal nature; or may lead to strong pressure to address societal causes of death.

### Coronial system in England and Wales

There are currently 80 coronial areas; in 1985, there were some 159 coronial districts.<sup>1930</sup> Each of those districts operated independently. There was, then, no Chief Coroner who could give national guidance on coronial practice. Coroners in each area were autonomous judicial officers operating with no oversight or guidance by a central body. They had to work within the law that gave them their powers to act, but with a “new” disease, such as AIDS, there was no structure to guide them in their decisions about when an inquest was required.

Under the Coroners Act 1887, the circumstances in which an inquest was required included when “*there is reasonable cause to suspect that such person has died either a violent or an unnatural death, or has died a sudden death of which the cause is unknown*”.<sup>1931</sup> This Act also established the four questions that continue to be answered by inquests today: “*who the deceased was, and how, when, and where the deceased came by his death*”.<sup>1932</sup>

The coroner had a power to request a post-mortem without an inquest taking place,<sup>1933</sup> and where they were satisfied that an inquest was unnecessary, she or he was obliged to send the registrar of deaths a certificate stating the cause of death as confirmed by a medical practitioner.<sup>1934</sup>

Within five days of the completion of the inquest, the coroner was obliged to send to the registrar of deaths a certificate setting out information concerning death, the particulars of

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1928 The Shipman Inquiry *Third Report: Death Certification and the Investigation of Deaths by Coroners* July 2003 para 9.84 RLIT0001826

1929 However, some participants in inquests – particularly family members – would describe the process as adversarial. See, for example, the 2009 Cullen Review into FAls in Scotland which described the sheriff courts as “*intimidating and tend to have an adversarial atmosphere.*” Review of Fatal Accident Inquiry Legislation 2009 para 3.3 RLIT0001836

1930 The Functions of Coroners p1 HOME0000060\_006

1931 Coroners Act 1887 section 3 p3 RLIT0002255

1932 Coroners Act 1887 section 4(3) p4 RLIT0002255

1933 Other than in cases of a violent or unnatural death, or a death in prison. Coroners Act 1988 section 19 pp17-18 RLIT0002273

1934 Coroners Act 1988 section 19(3) p18 RLIT0002273

death required by the Births and Deaths Registration Act 1953 and specifying the time and place at which the inquest was held.<sup>1935</sup>

In addition, Rule 43 of the Coroners Rules 1984 provided that: “A coroner who believes that action should be taken to prevent the recurrence of fatalities similar to that in respect of which the inquest is being held may announce at the inquest that he is reporting the matter in writing to the person or authority who may have power to take such action and he may report the matter accordingly.”<sup>1936</sup> There has been no evidence that this power was used by a coroner in relation to the use of infected blood and blood products.

In 2013 wide-scale reforms to the coronial system were introduced in England and Wales.<sup>1937</sup> This included the creation of the role of Chief Coroner, as judicial head of the coronial system. This represented a fundamental change. It provides a means by which central guidance can be published and oversight of the processes can be provided. The role of the Chief Coroner includes providing support, leadership and guidance for coroners in England and Wales; keeping a register of coronial investigations lasting more than 12 months; publishing Prevention of Future Death reports and responses; and monitoring the system of recommendations from inquests being reported to the appropriate authorities in order to prevent further deaths. In performing this role, the Chief Coroner has issued guidance, law sheets and advice on a variety of matters.<sup>1938</sup>

Where a death is reported to a coroner, the coroner will make preliminary enquiries and undertake an investigation. A senior coroner may require a post-mortem to be carried out.<sup>1939</sup> If the coroner is satisfied that the cause of death is clear, the coroner may decide that there is no need to carry out a post-mortem examination or to hold an investigation,<sup>1940</sup> unless the coroner has reason to suspect that the deceased died a violent or unnatural death or died while in custody or state detention.<sup>1941</sup>

An inquest (where no jury is required) may be held through a hearing or in writing. An inquest can be in writing when the coroner decides a hearing is unnecessary, provided they have invited representations from each interested person and it appears that there is no real prospect of disagreement as to the determination or findings that the inquest could or should make and no public interest would be served by a hearing.<sup>1942</sup>

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1935 Coroners Act 1988 section 11(7) p12 RLIT0002273

1936 Coroners Rules 1984 rule 43 p10 RLIT0002257. This power was first provided in: The Coroners (Amendment) Rules 1980 section 11 p3 RLIT0002253

1937 Through the Coroners and Justice Act 2009 RLIT0002266 and accompanying secondary legislation, including the Coroners (Inquests) Rules 2013 RLIT0002260. More recently, the Notification of Deaths Regulations 2019 have also come into force.

1938 For more information about the Chief Coroner, see: House of Commons Library *Briefing Paper: The Office of the Chief Coroner* 19 February 2021 RLIT0002258

1939 Coroners and Justice Act 2009 section 14 p18 RLIT0002266

1940 Coroners and Justice Act 2009 section 4(1) p14 RLIT0002266

1941 Coroners and Justice Act 2009 section 4(2) p14 RLIT0002266

1942 Coroners and Justice Act 2009 section 9C RLIT0002266; as inserted by: Judicial Review and Courts Act 2022 section 40 RLIT0002309

An inquest is to determine:

- “(a) *who the deceased was;*
- (b) how, when and where the deceased came by his or her death;*
- (c) the particulars ... to be registered concerning the death.”*<sup>1943</sup>

These questions are broadened to include the question of “*in what circumstances the deceased came by his or her death*” when Article 2 of the European Convention on Human Rights (the right to life) is engaged.<sup>1944</sup> In the medical context, it is only engaged where cases demonstrate systemic or structural dysfunction rather than “*mere*” negligence.<sup>1945</sup>

A determination by the coroner – in the old language, a verdict – which gives the answers to the questions listed above cannot be framed in such a way to suggest either criminal liability on the part of a named person, or civil liability.<sup>1946</sup> A coroner, or a jury,<sup>1947</sup> is forbidden from expressing an opinion about any matter other than the questions set out above.<sup>1948</sup>

A determination can be given with a variety of possible “*short-form*” conclusions including accident or misadventure, lawful/unlawful killing, natural causes, or an open verdict and/or can comprise a brief narrative conclusion expressed in concise and ordinary language so as to indicate how the deceased came by their death.<sup>1949</sup>

Provision is made for a coroner to produce a Prevention of Future Deaths report<sup>1950</sup> where “*anything revealed by the investigation [of the coroner] gives rise to a concern that circumstances creating a risk of other deaths will occur, or will continue to exist, in the future, and in the coroner’s opinion, action should be taken to prevent the occurrence or continuation of such circumstances, or to eliminate or reduce the risk of death created by such circumstances.*” A Prevention of Future Deaths report will be issued to people or organisations “*who the coroner believes may have power to take such action*” and they must respond explaining what actions have been taken to reduce that risk.<sup>1951</sup>

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1943 Coroners and Justice Act 2009 section 5(1) pp14-15 RLIT0002266

1944 Coroners and Justice Act 2009 section 5(2) p15 RLIT0002266. See: *R v HM Coroner for the Western District of Somerset ex parte Middleton* 11 March 2004 RLIT0001972

1945 See: *Lopes de Sousa Fernandes v Portugal* Judgment 19 December 2017 RLIT0002324, *Fernandes de Oliveira v Portugal* Judgment 31 January 2019 RLIT0002325, *R (Maguire) v HM Senior Coroner for Blackpool & Fylde and Another* 21 June 2023 RLIT0002326

1946 Coroners and Justice Act 2009 section 10(2) p16 RLIT0002266

1947 An inquest is usually held without a jury unless the senior coroner has reason to suspect that the death was a violent or unnatural one, the cause of death is unknown, or the deceased died while in custody or otherwise in state detention. A jury must be used where a death resulted from the act or omission of a police officer or a member of a service police force or where the death was caused by a notifiable accident, poisoning or disease. Coroners and Justice Act 2009 section 7 p15 RLIT0002266. An accident, poisoning or disease is notifiable if notice is required under an Act to a government department or under section 19 of the Health and Safety at Work etc. Act 1974. Coroners and Justice Act 2009 section 7(4) p15 RLIT0002266

1948 Coroners and Justice Act 2009 section 5(3) p15 RLIT0002266

1949 The Coroners (Inquests) Rules 2013 notes 9(i-ii) p12 RLIT0002260

1950 These have replaced the power under Rule 43 of: The Coroners Rules 1984 RLIT0002257

1951 Coroners and Justice Act 2009 para 7, schedule 5 p158 RLIT0002266, Coroners (Investigations) Regulations 2013 section 28 p8 RLIT0002295

## Fatal Accident Inquiry system in Scotland

Investigations into deaths in Scotland fall within the responsibility of the Crown Office and Procurator Fiscal Service (“COPFS”). Prior to 2013, the COPFS was organised into 11 areas, each of which was headed by an area procurator fiscal, who was responsible for the work of his or her area and accountable to the Lord Advocate.<sup>1952</sup> Each of the 11 areas had a dedicated deaths unit or area deaths specialist and there was a senior member of legal staff assigned to supervise the investigations of deaths.<sup>1953</sup> In 2013 the Scottish Fatalities Investigation Unit, a specialist division of the Crown Office, was established to investigate all sudden, unexpected, and unexplained deaths in Scotland.<sup>1954</sup> The relevant statutory framework, prior to 2016 when new legislation was introduced, was the Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act 1976.<sup>1955</sup>

Under the 1976 Act, when it “*appears to the Lord Advocate to be expedient in the public interest*” that an inquiry should be held on the ground that the death was sudden, suspicious or unexplained, or it had occurred in circumstances such as to give rise to serious public concern, a fatal accident inquiry (“FAI”) was to be held.<sup>1956</sup> This wording left a considerable discretion to the Lord Advocate. Where such an inquiry was held, there was no requirement for a sheriff to sit with a jury<sup>1957</sup> and at the conclusion of the evidence and submissions, the sheriff had to make a determination:

- “(a) *where and when the death and any accident resulting in the death took place;*
- “(b) *the cause or causes of such death and any accident resulting in the death;*
- “(c) *the reasonable precautions, if any, whereby the death and any accident resulting in the death might have been avoided;*
- “(d) *the defects, if any, in any system of working which contributed to the death or any accident resulting in the death; and*
- “(e) *any other facts which are relevant to the circumstances of the death.*”<sup>1958</sup>

At the conclusion of the FAI, the sheriff clerk had to send the Lord Advocate a copy of the determination of the sheriff and, on a request being made to him, send to any minister or

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1952 Review of Fatal Accident Inquiry Legislation 2009 para 2.12 RLIT0001836

1953 Review of Fatal Accident Inquiry Legislation 2009 para 2.13 RLIT0001836

1954 Crown Office and Procurator Fiscal Service *Reporting deaths to the Procurator Fiscal: Information and Guidance for Medical Practitioners* 2015 p3 COPF0000107

1955 The Fatal Accidents Inquiry (Scotland) Act 1895 first introduced mandatory public inquiries before a sheriff and jury into the causes and circumstances of fatal accidents in the course of industrial employment. The Fatal Accidents Inquiry (Scotland) Act 1906 amended the 1895 Act to include issues of fault or negligence and for the Lord Advocate to direct that an inquiry be held where it appeared to be expedient in the public interest to investigate a sudden or suspicious death. Review of Fatal Accident Inquiry Legislation 2009 paras 2.1-2.2 RLIT0001836. The Fatal Accidents and Sudden Deaths Procedure (Scotland) Rules 1977 became the governing procedural rules.

1956 The Act required deaths at work or in custody to be investigated by the procurator fiscal: the text considers the rule in all other cases. Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act 1976 section 1(1)(b) p1 RLIT0002265

1957 Unlike its predecessor Acts. Review of Fatal Accident Inquiry Legislation 2009 para 2.3 RLIT0001836

1958 Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act 1976 section 6(1) p6 RLIT0002265



government department or to the Health and Safety Commission a copy of key documents (such as the inquiry transcript, reports and the determination).<sup>1959</sup> However, the sheriff was not permitted to make any finding of fault or negligence.<sup>1960</sup>

In 2009, the report of a review chaired by Lord Cullen was published considering the FAI legislation. Lord Cullen described the “*wide discretion*” given to the Lord Advocate in a variety of situations:

*“such as an unexplained death in hospital or a death in circumstances suggesting a risk to public health or safety or a road accident on a bad stretch of road. Where there is a question of a discretionary FAI, the procurator fiscal has to report to the deaths unit which is part of the High Court Unit in Crown Office, with the views of the relatives of the deceased and his or her recommendations. It is for Crown Counsel, in consultation with the Law Officers where appropriate, to decide whether a discretionary FAI should be held, and for the procurator fiscal to apply for one if so instructed. A decision of the Lord Advocate to decline to apply for the holding of a discretionary FAI is open to challenge by judicial review.”*<sup>1961</sup>

He noted that of the 14,000 or so deaths reported each year, half were investigated by a procurator fiscal and “*the need for an FAI arises in only a very small fraction of the cases.*”<sup>1962</sup>

The Cullen Review made a number of recommendations, many of which were implemented by the Inquiries into Fatal Accidents and Sudden Deaths etc (Scotland) Act 2016 (“the 2016 Act”). Under the 2016 Act there are several circumstances (that fall outside the remit of this Inquiry) where it is mandatory to hold an FAI.<sup>1963</sup> Under the heading “*Discretionary inquiries*” the Act requires an FAI:

*“if the Lord Advocate—*

*(a) considers that the death—*

*(i) was sudden, suspicious or unexplained, or*

*(ii) occurred in circumstances giving rise to serious public concern, and*

*(b) decides that it is in the public interest for an inquiry to be held into the circumstances of the death.”*<sup>1964</sup>

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1959 Fatal Accidents and Sudden Deaths Inquiry (Scotland) Act 1976 section 6(4) p6 RLIT0002265

1960 Review of Fatal Accident Inquiry Legislation 2009 para 2.9 RLIT0001836

1961 Review of Fatal Accident Inquiry Legislation 2009 para 2.15 RLIT0001836. It was the decision of the Lord Advocate to decline an FAI in relation to deaths from HIV that led to a judicial review, which ruled that the deaths should be investigated, which in turn led to the establishment of the Penrose Inquiry.

1962 Review of Fatal Accident Inquiry Legislation 2009 para 2.14 RLIT0001836

1963 For example, it is mandatory for an inquiry to be held into the death of a person which occurred in Scotland and was the result of an accident while a person was acting in the course of their employment or occupation: section 2(3) of the 2016 Act. It is also mandatory for an inquiry to be held where a person died in Scotland and they were in legal custody or were a child in secure accommodation: section 2(4) of the 2016 Act. There are exceptions under section 3 of the 2016 Act.

1964 Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 section 4 p3 RLIT0002263. Where the Lord Advocate decides not to hold an inquiry the Lord Advocate must give reasons, if

This wording, like the wording in the 1976 Act, gives a considerable discretion to the Lord Advocate.

When an FAI is to be held, a procurator fiscal must investigate the circumstances of a death and arrange for the inquiry, which will be conducted by a sheriff.<sup>1965</sup> The sheriff must determine:

- “(a) when and where the death occurred,*
- (b) when and where any accident resulting in the death occurred,*
- (c) the cause or causes of the death,*
- (d) the cause or causes of any accident resulting in the death,*
- (e) any precautions which–*
  - (i) could reasonably have been taken, and*
  - (ii) had they been taken, might realistically have resulted in the death, or any accident resulting in the death, being avoided,*
- (f) any defects in any system of working which contributed to the death or any accident resulting in the death,*
- (g) any other facts which are relevant to the circumstances of the death.”*<sup>1966</sup>

The COPFS guidance for medical practitioners states that the doctor with the most detailed knowledge of the circumstances of a reportable death should report it to the procurator fiscal who may require discussion of the circumstances and will decide to what extent further investigation is required.<sup>1967</sup>

Reportable deaths include those with an unnatural cause (including deaths due to adverse drug reactions reportable under the Yellow Card scheme) and those with a natural cause where:

- (a) the cause of death cannot be identified by a medical practitioner to the best of her or his knowledge and belief;
- (b) the death may be related to a suggestion of neglect;
- (c) there is an allegation or possibility of fault on the part of another person, body or organisation;

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reasons are requested by the deceased’s spouse, civil partner, “common-law” partner or nearest known relative: Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 section 9 p5 RLIT0002263

1965 Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 sections 1(1), 1(2) p1 RLIT0002263

1966 Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 section 26(2) p12 RLIT0002263

1967 Crown Office and Procurator Fiscal Service *Reporting deaths to the Procurator Fiscal: Information and Guidance for Medical Practitioners* 2015 p3, p8 COPF0000107

- (d) the death is from an infectious disease;
- (e) deaths have occurred under medical care in circumstances which are the subject of concern or complaint to the nearest relatives, might indicate fault and/or are likely to be subject to an Adverse Event Review by Healthcare Improvement Scotland;
- (f) a death certificate has been issued and a complaint is later received by a doctor or health board that suggests an act or omission by medical staff caused or contributed to the death.<sup>1968</sup>

The procurator fiscal may accept the death certificate offered and take no further action, consent to a hospital post-mortem, request a police report, or instruct a post-mortem examination, and can instruct an independent expert in the relevant field to provide an opinion on the circumstances of the death. A post-mortem can be a full post-mortem or a “view and grant” which involves an external examination and consideration of the medical history and circumstances of the death and then granting of a death certificate. After the initial investigations, the procurator fiscal may decide that it is in the public interest to hold an FAI.<sup>1969</sup>

The purpose or role of an FAI is not to establish civil or criminal liability.<sup>1970</sup> The sheriff has the power to make a recommendation which might realistically prevent other deaths in similar circumstances,<sup>1971</sup> which must be responded to by the person to whom the recommendation is made setting out what the respondent has done or proposed to do, or if no action has or will be taken, the reasons for that.<sup>1972</sup>

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1968 Crown Office and Procurator Fiscal Service *Reporting deaths to the Procurator Fiscal: Information and Guidance for Medical Practitioners* 2015 pp4-6 COPF0000107

1969 Crown Office and Procurator Fiscal Service *Reporting deaths to the Procurator Fiscal: Information and Guidance for Medical Practitioners* 2015 pp8-10 COPF0000107. See also: Guidance for Doctors Completing Medical Certificates of the Cause of Death (MCCD) and its Quality Assurance September 2018 RLIT0001096. In the context of medical deaths, in evidence to this Inquiry, the COPFS has set out how in practice this guidance is implemented: “*the Procurator Fiscal will discuss with the reporting doctor the circumstances surrounding the death and any relevant medical history to determine whether a cause of death can be appropriately certified. In some cases, the doctor may be invited to seek further guidance on certification from a doctor based within the Death Certification Review Service (DCRS) (which is run by Healthcare Improvement Scotland). Following those discussions, where the reporting doctor is unable to issue an appropriate certificate of cause of death, the Procurator Fiscal will instruct a post mortem examination to enable a pathologist to determine the cause of death based on the autopsy findings and medical history.*” Letter from Katrina Parkes to the Infected Blood Inquiry 1 September 2022 p2 COPF0000105

1970 Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 section 1(4) p1 RLIT0002263

1971 Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 sections 26(1)(b), (4) p12 RLIT0002263. Lord Cullen had found that sheriffs made such recommendations in about one third of FAIs, although there was no explicit provision in the Act which empowered them to do so. Review of Fatal Accident Inquiry Legislation 2009 para 3.25 RLIT0001836

1972 Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 section 28 pp13-14 RLIT0002263

After a determination is made, the procurator fiscal must give the name and last known address and the date, place and cause of death to the Registrar General of Births, Deaths and Marriages for Scotland.<sup>1973</sup>

It should be emphasised that this section has set out the position as it now is, following Lord Cullen’s recommendations – and represents a change from, and improvement of, the previous arrangements which operated in respect of most of the deaths with which this Inquiry has been concerned.

### Coronial system in Northern Ireland

Before 2006 there were seven coroners’ districts with each district having a coroner and deputy coroner. In 2006 the Coroners Service for Northern Ireland became a centralised body.

The Coroners Act (Northern Ireland) 1959 provides that:

*“Every medical practitioner, registrar of deaths or funeral undertaker and every occupier of a house or mobile dwelling and every person in charge of any institution or premises in which a deceased person was residing, who has reason to believe that the deceased person died, either directly or indirectly, as a result of violence or misadventure or by unfair means, or as a result of negligence or misconduct or malpractice on the part of others, or from any cause other than natural illness or disease for which he had been seen and treated by a registered medical practitioner within twenty-eight days prior to his death, or in such circumstances as may require investigation (including death as the result of the administration of an anaesthetic), shall immediately notify the coroner within whose district the body of such deceased person is of the facts and circumstances relating to the death.”*<sup>1974</sup>

A coroner may hold an inquest in any of those circumstances or where there has been an unexpected or unexplained death, or a death in suspicious circumstances.<sup>1975</sup> An inquest may be held without a jury but a jury must be summoned where *“the death occurred in circumstances the continuance or possible recurrence of which is prejudicial to the health or safety of the public or any section of the public”*.<sup>1976</sup> From 1980, coroners in Northern Ireland had the power to report to *“the person or authority who may have power”* to take action *“to prevent the occurrence of fatalities similar to that in respect of which the inquest is being held.”*<sup>1977</sup>

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1973 Inquiries into Fatal Accidents and Sudden Deaths etc. (Scotland) Act 2016 section 27(6) p13 RLIT0002263

1974 Coroners Act (Northern Ireland) 1959 section 7 p4 RLIT0002256

1975 Coroners Act (Northern Ireland) 1959 section 13 p6 RLIT0002256

1976 Coroners Act (Northern Ireland) 1959 section 18(1) p9 RLIT0002256

1977 Coroners (Practice and Procedure) Rules (Northern Ireland) 1980 p4 RLIT0002296, Inquests and Post-Mortem Examinations 1963 p5 WITN7589003

## Issues arising in death reporting and investigations

### Broad-brush clinician-dependent decisions

In the past, the contents of a death certificate were often broad-brush and the details provided were heavily dependent on individual clinical decisions. This remains the position today. The Public Health and Administration Expert Group evidence to the Inquiry was that:

*“Death certificates will record a number of different causes of death and which is given priority is up to the person who is filling that certificate. So everyone at the end of their life dies of cardiac arrest, that’s the common theme, that might be the top, but what is underlying that is the question and I think that will vary from clinician to clinician what they put in. There probably are fashions with what goes on the death certificate. So I think for a broad brushstroke of one of the things killing people in the UK, they are very valuable but for very detailed work they are a bit too coarse.”*<sup>1978</sup>

### Lack of guidance and training to doctors

In addition, there was little to no guidance and training available to doctors during the relevant period on how to fill out death certificates. Mark Petrie, a cardiologist, in an internal email about retrospective analysis of death certificates during the Penrose Inquiry, noted that: *“Very little guidance was given with regards to how to fill in death certificates. Doctors have traditionally filled these important forms in with no formal training. I am not sure if this has now changed ... The death certificate is important but given that these are usually filled in by junior doctors and the formal summary of admission by senior doctors most people would recognise that the discharge summary was preeminent.”*<sup>1979</sup>

A joint report of the Royal College of Physicians and the Royal College of Pathologists in 1982 had identified the need for training at medical schools, for recently qualified doctors and refresher courses: *“Unless doctors are adequately instructed ... the certificate will simply represent, to them, another example of an irritating and somewhat incomprehensible administrative procedure.”*<sup>1980</sup>

A Home Office pathologist, Professor Bernard Knight wrote to the Registrar General in February 1988 expressing concern about unsatisfactory causes of death being accepted by registrars. He went on to say:

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1978 (Professor Charles Vincent) Publication Health and Administration Expert Panel Transcript 3 October 2022 p107 INQY1000251. The evidence of the Statistics Expert Group was to similar effect. (Professor Stephen Evans) Statistics Expert Panel Transcript 9 November 2022 pp38-41 INQY1000258

1979 Email chain between Mark Petrie and Tracey Turnbull 24 February 2011 PRSE0001247. A discharge summary is a report made by the treating hospital doctor to the patient’s GP upon their discharge from further hospital treatment. It should summarise the treatment given, and the reasons for giving it. It will generally be narrative rather than tick box in style.

1980 Royal College of Physicians and Royal College of Pathologists *Medical Aspects of Death Certification* October 1982 p11 HOME0000058\_028

*“I realise that registrars cannot be expected to have significant medical knowledge and I do not know what the answer may be to this problem without screening by a more senior or experienced doctor ... Junior house officers and even more senior hospital doctors, together with general practitioners, have a very poor appreciation of death certification and even when they are aware of the true disease process, the way in which they write the certificate is often unacceptable.”*

This was reported in a memo within the General Register Office and there was further discussion with the BMA when it was agreed that further training would assist.<sup>1981</sup>

On 23 March 1996, a letter was published in *The Lancet* in which it was noted that Professor Michel Coleman, deputy chief statistician at the Office of Population Censuses and Surveys (“OPCS”), had received legal advice on the meaning of “unnatural death”<sup>1982</sup> and was proposing “to issue revised guidance to doctors and registrars of deaths which makes it clear that HIV-related deaths must ordinarily be regarded as ‘natural’.”<sup>1983</sup> However, it does not appear that any such guidance was ever produced.

The lack of guidance and training for doctors severely hampered the accurate recording of the cause of death of many people and gave rise to disparities of practice. Given the need for sensitivity, and the anxieties around recording publicly the fact of someone’s infection, guidance was urgently required.

### **Difficulties with post-mortem facilities**

Moreover, there were concerns about the facilities for post-mortem examinations, particularly in the 1980s because of concerns about perceived risks to staff. A letter from Dr G Sutton, deputy medical referee, City of Wakefield, to the Home Office on 4 July 1988 stated that “*Our Health and Local Authorities are drawing up policies for AIDS, which will cover, inter alia, advice on disposal of the dead and would discourage post mortems except at a Coroner’s request.*”<sup>1984</sup> At the Coroner’s Working Party on 20 November 1989 “*Dr Burton [from the Coroners’ Society] considered that post-mortem examinations should not normally be carried out on AIDS victims. If a post-mortem was necessary, it should be possible to arrange for this to take place at a centre specialising in the treatment of AIDS or those provided with facilities for remote post-mortem examinations.*” The Department of Health was to be asked for details of pathologists willing to conduct these post-mortem examinations and they in turn agreed to discuss this with the Royal College of Pathologists.<sup>1985</sup>

1981 Memo from W Jenkins to Dr J Ashley 29 June 1989 p1 WITN7591016, Written Statement of Mark Flynn paras 6.4-6.5 WITN7591015. The training would usually be prescribed by the Royal Colleges.

1982 Letter from Helen Jenn to Professor Coleman 8 January 1996 DHSC0006199\_009

1983 Brahams *Unnatural death, AIDS, and coroners* The Lancet 23 March 1996 DHSC0006199\_002

1984 Letter from Dr Sutton to the Home Office 4 July 1988 MOJU0000013\_079, Letter from R Snow to Dr Sutton 12 July 1988 MOJU0000013\_078

1985 Minutes of Coroners’ Working Party meeting 20 November 1989 p2 MOJU0000013\_053, Letter from G Harrison to Dr Susan Lader 28 March 1990 MOJU0000013\_040

These concerns appear to have extended to post-mortems where the deceased had hepatitis: one woman recalls that her mother's request that a post-mortem be carried out to investigate her father's death was refused because he had hepatitis, and it would require the room to be fumigated. His cause of death was recorded solely as leukaemia.<sup>1986</sup>

On 7 October 1991, Dr (later Professor) Charles Hay, then the director of the Liverpool Haemophilia Centre, noted that *"The number of deaths from liver disease is undoubtedly increasing but it is to some extent masked by the effect of HIV ... Cirrhosis may not be the primary cause of death and will therefore not necessarily appear on the death certificate. It is also more difficult to obtain post mortem examinations in HIV seropositive patients, either because of lack of local facilities or because of resistance from the relatives, and many cases of cirrhosis may therefore be missed for this reason."*<sup>1987</sup>

It seems therefore that concerns about the risks of post-mortem examinations may have resulted in an underreporting of hepatitis as well as HIV, particularly where the deceased was co-infected with HIV.

### **Conscious decisions not to record the cause of death accurately or transparently**

Alongside these systemic issues, it is also clear that the decision not to record HIV or hepatitis on a death certificate was sometimes a conscious one, which was made for a variety of reasons.

One woman describes her father's death certificate recording heart failure as the cause of death because *"This was at a time when no-one put HIV/AIDS or any related illnesses on death certificates if at all possible for sensitive reasons and so that life assurance policies and the like would pay out. I believe the accumulative affects of the combination of HIV and HCV actually killed him."*<sup>1988</sup> A woman was advised to have bronchopneumonia recorded on her husband's death certificate: *"The Doctor advised me that this was the best course of action as if AIDS was on the certificate we wouldn't find anyone to bury him and that a cremation would be our only option (which is not what my husband wanted)."*<sup>1989</sup> Fiona Weeks' sister died of HIV contracted through a blood transfusion and she describes a discussion about what should go on the death certificate: *"[The doctor] asked me what I wanted the death certificate to say. I didn't understand. He said he could put the illness that killed her on the certificate instead of AIDS but that if anyone asked he would have to tell them it was AIDS related. He said if AIDS was on the certificate insurance wouldn't pay out. At the time I couldn't give a damn, but he was brilliant. He put Encephalitis on the death certificate."*<sup>1990</sup>

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1986 Written Statement of ANON paras 9-12, para 23 WITN0695001

1987 Letter from Dr Charles Hay to Graham Barker 7 October 1991 HSOC0012308

1988 Written Statement of ANON para 21 WITN1449001

1989 Written Statement of ANON para 34 WITN1330001

1990 Written Statement of Fiona Weeks para 42 WITN0708001

One woman was told by a doctor that “*it was in my best interest not to record*” her husband’s HIV status on his death certificate.<sup>1991</sup> Another woman describes how Dr Christopher Ludlam took her mother aside when their father died and “*explained that he wasn’t going to put HIV as the cause of death on my father’s death certificate. Dr [Ludlam] said that in his opinion my father would not have wanted it listed as the cause of his death. Instead ... I think it states he had a brain haemorrhage.*”<sup>1992</sup>

Deborah James, whose brother’s death in 1982 following a contaminated transfusion was recorded as solely due to Hodgkin’s disease, says:

*“Upon Glyn’s passing medical staff told my Mother and Father that if they consented to the cause of death being Hodgkin’s and not hepatitis C (HCV) then the family could avoid a post mortem and that ultimately ‘nothing would bring him back’. My Mother was adamant that she did not want a post mortem carried out on my brother as he had already been through enough. As such my parents consented to the cause of death being Hodgkin’s on the death certificate and not hepatitis C (HCV).”*<sup>1993</sup>

Some families made a specific request for the information to be withheld from the certificate. One woman promised her husband, infected with HIV and Hepatitis C from blood products, “*that if he died the word ‘HIV’ would not be on his death certificate*” because he was “*extremely worried about people finding out that he had HIV.*”<sup>1994</sup> Amanda Patton recalls her mother “*saying to the doctor after [her brother] Simon’s death that nothing mentioning ‘AIDS’ should go on his death certificate.*”<sup>1995</sup> One person whose father was infected with Hepatitis C and HIV says: “*We made sure when my father died that his death certificate did not mention HIV or hepatitis C. It just says liver failure and states the symptoms of death rather than the cause to stave off any stigma attached to the hepatitis C infection.*”<sup>1996</sup> Rita Wood says that the family asked the doctors to keep HIV off the death certificate because of the stigma involved.<sup>1997</sup> Nina Douglas’ mother pleaded with the registrar to remove AIDS from the death certificate of her father.<sup>1998</sup>

Mary Grindley said after her husband John’s death: “*I don’t think John would have been too worried about what they wrote but my first thought was for my son. I told them I didn’t want HIV or AIDS on the death certificate. Initially, they offered to put Haemophilia on it but I did not agree to this because he didn’t die of Haemophilia. In the end, they just put pneumonia on the certificate, which in fairness is what finally killed him.*”<sup>1999</sup>

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1991 Written Statement of ANON para 29 WITN1284001

1992 Written Statement of ANON paras 16-17 WITN1295001

1993 Written Statement of Deborah James paras 8.2-8.3 WITN2357001

1994 Written Statement of ANON para 22 WITN1380001

1995 Written Statement of Amanda Patton para 39 WITN0042001

1996 Written Statement of ANON para 5.13 WITN2507001

1997 Written Statement of Rita Wood para 25 WITN3316001

1998 Written Statement of Nina Douglas para 36 WITN1644001

1999 Written Statement of Mary Grindley para 5.28 WITN2336001



However, Janet Kenny’s son was “adamant” that Hepatitis C should be recorded on her husband’s death certificate.<sup>2000</sup> Philip Cuthbert describes his feelings that his father’s death certificate does not refer to AIDS, HIV, Hepatitis C “or even haemophilia”, saying “I feel that even on my dad’s death certificate, they are trying to cover up the truth.”<sup>2001</sup> Another person says of their father that: “The cause of his death was recorded as pneumocystis pneumonia. I am angry that this was recorded on his death certificate, and that there was no reference to HIV or contaminated blood products. At the time, the doctors suggested they were protecting me by not recording HIV, when I think they were protecting themselves.”<sup>2002</sup>

Irene Fitzpatrick said that when her son, Gary, was reaching the end of his life she was taken into a room by the doctor: “he asked me what I wanted put on the death certificate. I said I wanted the truth put on it and he said I would get reporters at my door if it said that Gary had died from HIV. I knew he was just trying to scare me”. She said: “I was lucky Gary died at home because the GP came round and he agreed that HIV should be stated on the death certificate as the cause of his death.”<sup>2003</sup>

Although there is no doubt that Denise and Colin Turton’s son Lee died of AIDS, as reflected in a form completed as part of a survey of patients treated at haemophilia centres in the UK, Lee’s death certificate made no reference to AIDS; instead the cause of death was given as “la pneumonia II Haemophilia”.<sup>2004</sup>

The death certificates for Susan Hallwood’s two sons, who were infected with HIV by their treatment at Alder Hey, record bronchopneumonia and haemophilia, and pneumonia and haemophilia as the causes of death.<sup>2005</sup> Susan told the Inquiry that it was not haemophilia that killed them – it was AIDS and AIDS should have been on the death certificates: “they’ve got no right to put haemophilia. God knows what they’re putting haemophilia for. They didn’t die of haemophilia.”<sup>2006</sup> The death certificates of Lauren Palmer’s parents do not record their real cause of death – HIV/AIDS – and Lauren told the Inquiry “I can see why back then it was maybe something that would be for the best. However, I think now we need the truth out there ... It shouldn’t be hidden any more ... it is important now to have the real cause of death on the death records.”<sup>2007</sup>

These varying reasons for not including the correct cause of death on the death certificate are reflected in the contemporaneous documents. On 5 February 1987, the BMA’s *The Doctor* magazine quoted a specialist in community medicine as saying that doctors were not recording AIDS on death certificates because “They don’t want to upset relatives, so

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2000 Written Statement of Janet Kenny para 140 WITN0338001

2001 Written Statement of Philip Cuthbert para 27 WITN7380001

2002 Written Statement of ANON para 20 WITN3113001

2003 Written Statement of Irene Fitzpatrick para 30 WITN3513001

2004 Lee Turton Death Certificate 22 January 1922 p1 WITN1574004

2005 Brian Hallwood Death Certificate 13 May 1994 WITN1267020, Stephen Hallwood Death Certificate 19 October 1989 WITN1267021

2006 Susan Hallwood Transcript 29 September 2022 p50 INQY1000249

2007 Lauren Palmer Transcript 7 May 2019 p28 INQY1000005

*we may not have accurate figures about how many people are dying from AIDS,' explained Dr Marvin Schweiger, Leeds' medical officer for environmental health ... He called on doctors to ask themselves whether it was morally right to give misleading information when it was so important that accurate statistics were compiled in order to plan 'sensibly' for the growing AIDS epidemic."*<sup>2008</sup>

On 13 May 1987, Tony Newton, Minister for Health, and Sir Donald Acheson, CMO, gave evidence to the Social Services Committee of the House of Commons. Tony Newton acknowledged the sensitivities in reporting AIDS and HIV on a death certificate and noted that:

*"it is possible for certifying doctors to indicate by ticking a box on the certificate that they have further information that they will make available to the OPCS2009 in confidence. That method is in fact known to be used ... It seems to me actually in practice there are probably quite a number of circumstances in which doctors find a way ... to minimise the impact on the relatives of what they put on the death certificates at the very least in quite a number of circumstances."*

Sir Donald affirmed this view and said *"this is true both in the case of cirrhosis of the liver and, for example, with syphilis in days gone by, that doctors have hesitated to put it on the death certificate and there has been this arrangement whereby it can be added in the confidential way."*<sup>2010</sup>

At a meeting of the Expert Advisory Group on AIDS ("EAGA") the following summer chaired by the CMO Sir Donald, the Department of Health and Social Security reported that they had made enquiries about the legality of *"using a 'Box B' marking on a death certificate in order to maintain confidentiality"* but the OPCS had responded that "Box B" was designed to be used when results were due to come through later and give more information about the cause of death. The minutes record that *"Members noted the position."*<sup>2011</sup>

In a letter on 5 October 1989, a civil servant within the Home Office, G Harrison, asked the General Register Office whether a new confidential box should be added to death certificates to allow doctors to tick whether a death was related to AIDS. This was suggested as a compromise to respect the need for privacy for families but still ensure that investigation by the coroner was undertaken where necessary.<sup>2012</sup> The following month she updated the Coroners' Working Party that the General Register Office *"are not prepared to adopt*

2008 The Doctor *Death certificates hide AIDS truth* 5 February 1987 SHTM0000651

2009 Office of Population Censuses and Surveys ("OPCS").

2010 Social Services Committee *Problems Associated with AIDS* 13 May 1987 p58 WITN0771140

2011 Minutes of Expert Advisory Group on AIDS meeting 7 June 1988 p2 NHBT0010203

2012 Letter from G Harrison to W Jenkins 5 October 1989 pp1-2 MOJU0000013\_057. She noted: *"In general, if the virus was acquired by sexual means it would be regarded as a natural death, but it would be considered unnatural if AIDS was contracted by injection with a contaminated needle (drug addicts), by treatment with contaminated blood products (haemophiliacs) or by contamination with the bodily fluids of an AIDS victim (those assisting and treating the victims)."* In separate correspondence with David Watters of the Haemophilia Society she said: *"Coroners have taken the view that death resulting from HIV infection contracted from blood products which were later found to be contaminated is not natural and the Home Secretary has no power to comment on or intervene in this decision."* Letter from G Harrison to David Watters 21 September 1989 MOJU0000013\_059

*a confidential box procedure but they would be willing to consider issuing Registrars with guidance on how to deal with cases of haemophiliacs with AIDS and the Working Party will wish to consider whether this should be pursued.*<sup>2013</sup> The Working Party “agreed that haemophiliacs were a sensitive category” and were concerned that “the children of the deceased would be particularly affected” but took no particular action, perhaps because one of the two coroners present said that registrars had to decide whether to report AIDS cases to coroners and every case in his district was reported to him and the other said that if registrars did not question relatives they would have no option but to inform the coroner.<sup>2014</sup>

On 10 September 1990 Hazel Smith, HIV/AIDS prevention coordinator in the East Surrey Health Authority wrote to Susan Wilcox, Registrar of Births and Deaths at Redhill, saying:

*“At the last meeting of the E.S.H.A. [East Surrey Health Authority] AIDS Action Group, we discussed the problems of entering ‘acquired immunodeficiency syndrome’ (AIDS) or ‘human immunodeficiency virus (HIV) infection’ as the cause of death on a death certificate. The issue is basically the need to avoid breaching confidentiality after the patient’s death and thereby causing distress to the family, conflicting with the need to provide the statistics for epidemiological surveillance at the C.D.S.C.<sup>2015</sup> After consultation with the Terrence Higgins Trust and C.D.S.C. directly, it appears that there is a way around this problem. The certifying doctor states the cause of death as the opportunistic infection or cancer, etc (e.g. pneumonia or malignant melanoma); the underlying cause of death (part B) is left blank, and the box on the rear of the certificate, to say that further information will be forthcoming, is ticked and initialled. The Registrar then sends the doctor form SD17a, which can be completed with the medical information on AIDS/ HIV. This form is then forwarded by the doctor directly to O.P.C.S., and from there to the C.D.S.C., without the medical details being entered into the public record.”<sup>2016</sup>*

This approach was firmly rejected in the reply from the General Register Office:

*“May I first explain that S22(1) of the Births and Deaths Registration Act 1953 requires that a doctor who is in attendance on the deceased during his last illness should certify the cause of death to the best of his knowledge and belief. This certificate has to be on the prescribed form which requires doctors to include any underlying causes of death and any other significant conditions leading to death. However where a doctor believes he may be able to provide further information subsequent to certification, eg where the result of histological or microbiological tests become available later, he initials a box on his certificate indicating this to be the case. A follow up enquiry is issued and any further information that is returned subsequently is treated in confidence by OPCS and used for statistical*

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2013 Memo from G Harrison to the Coroners’ Working Party November 1989 p2 MOJU0000013\_055

2014 Minutes of Coroners’ Working Party meeting 20 November 1989 pp1-2 MOJU0000013\_053

2015 Communicable Disease Surveillance Centre.

2016 Letter from Hazel Smith to Susan Wilcox 10 September 1990 p33 WITN7591021

*purposes. This confidential procedure would be appropriate in suspected AIDS cases provided that at the time of certification there is some reason for doubt as to whether AIDS played a part in causing the death but it should not be used to evade full and proper certification. Indeed doctors who deliberately conceal information relating to a cause of death (including underlying causes), which it is evident to them at the time of certification should appear on the prescribed certificate, are acting unlawfully.”<sup>2017</sup>*

On 10 February 1992 at a meeting of the UK Regional Haemophilia Centre Directors Committee “*Dr Mayne asked if an agreed formula of wording for death certificates should be considered.*”<sup>2018</sup> By way of comment, once it became generally known that this formulation was being used any advantage of privacy for the family would be lost.

At the same meeting, it is recorded that “*Dr Hamilton said that there were good relationships with the Coroner in the Newcastle area; they never put HIV on the certificate but they made sure that the Coroner knew about it.*”<sup>2019</sup> Likewise, on 1 November 1993 at the UK haemophilia centre directors’ meeting, “*Dr Jones said that he did not put AIDS, etc. on the death certificate. There was some discussion about this and about the way that Directors filled in death certificates.*”<sup>2020</sup>

In her written evidence to the Inquiry, Dr Elizabeth Mayne said that she also did not put HIV on the death certificate:

*“This question highlights a very difficult and thorny problem which affected all doctors in managing HIV deaths. I took the decision not to put HIV as a primary cause of death after a meeting of the HCDO at which the issue was discussed at considerable length and taking into account the great sensitivity surrounding the matter for families in Northern Ireland, especially in rural communities ... There were a number of local religious reasons not to include HIV on the Death Certificate and there were also the paramilitaries who could use the information to exploit a family or individual. While HIV was not given as the primary cause of death, death certificates were filled in, in accordance with all rules and regulations. The primary cause of death, for example, pneumocystis pneumonia was stated. What was omitted was the secondary or tertiary cause of that pneumonia.”<sup>2021</sup>*

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2017 Letter from the General Register Office to Hazel Smith 4 October 1990 p29 WITN7591021. Emphasis in original.

2018 Minutes of UK Regional Haemophilia Centre Directors Committee meeting 10 February 1992 p6 HCDO0000443

2019 Minutes of UK Regional Haemophilia Centre Directors Committee meeting 10 February 1992 p6 HCDO0000443. This process would be of little use in providing public health information, or helping to prevent other deaths in similar circumstances.

2020 Minutes of UK Haemophilia Centre Directors meeting 1 October 1993 p6 HCDO0000493. In his written statement to this Inquiry, Dr Peter Jones, director of the Newcastle Haemophilia Centre, alluded to the practice of writing “*lymphoma*” and “*haemophilia*” on a death certificate being sufficient information for a doctor to infer that AIDS was the causal link without including it on the public record. However, he confirmed that each individual death involving HIV/AIDS was referred to the Coroner’s Officer. Written Statement of Dr Peter Jones para 103 WITN0841038

2021 Written Statement of Dr Elizabeth Mayne para 89 WITN0736009

The issue extended beyond the UK Haemophilia Centre Doctors' Organisation. In a West Sussex policy document, "*Control of Viral Hepatitis and Human Immunodeficiency Virus Infections*" which was published in 1994 it states "**Confidentiality must be maintained as in life.**<sup>2022</sup> *It may be appropriate to complete the death certificate in more general diagnostic terms. In this case the box offering 'further information' must be ticked.*"<sup>2023</sup>

There was also correspondence between Michael Burgess, secretary of the Coroners' Society and Dr Anna McCormick, senior medical statistician at the OPCS. On 3 April 1995, Michael Burgess wrote expressing concern that doctors:

*"may, on occasion, deliberately omit all or any reference to AIDS or HIV as being the (or an) underlying or contributory cause, even if fully aware of it. I understand that this may be because of the stigma for the family of having this on the certificate. Thus, a certificate is issued which is, on the face of it, incorrect (for effectively it does not represent their complete knowledge concerning the death); they seek to rectify by the use of Box B and the supplementary or additional information gathering process which is thus initiated ... Coroners remain concerned, therefore, that there is a divergence from the statutory requirement set out in S. 22 relating to these deaths ... In this way, some deaths which should be brought to the notice of the coroner are passed over by the registrar because of the inadequate certificate. **If the AIDS or HIV were contracted in circumstances which were violent or unnatural, e.g. through a contaminated needle or blood product,** a situation is being allowed to exist which may not, in the long run, be to the benefit of anyone, family, society, doctors or others because the opportunity to investigate these occurrences is being lost."*<sup>2024</sup>

A draft reply simply notes the law and says that "*OPCS policy is always to encourage doctors and registrars to fulfil the requirements of the law.*" It was indicated that training material was being prepared for medical students and doctors and that OPCS was reviewing the instructions for registrars regarding referral to coroners.<sup>2025</sup>

By 2000 the position was changing. The Department of Health responded to the Home Office who had been contacted by a GP acting as a medical referee for a crematorium. He was concerned that HIV was not always recorded on a death certificate as a contributory

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2022 This is an impossibility (in these terms) where death is due to a disease. Death certification requires that the cause of death be given. The law is that a person's medical details are sensitive personal information, and subject to restrictions on their processing – processing including, of course, publication or recording even in official documents. Whereas in life, these principles apply, where the public interest requires an accurate certification of death they simply cannot. What is implied must, therefore, be telling a half-truth in the certificate.

2023 *Control of Viral Hepatitis and Human Immunodeficiency Virus Infections* March 1994 p12 WSUS0000068. Emphasis in original.

2024 Letter from Michael Burgess to Dr McCormick 3 April 1995 p3 WITN7591020. Emphasis added. Some thought at the time that the cause of the infection was a critical matter to bring to light through death certification. However, even in 1995, coroners were very much autonomous, and had a very wide discretion as to what they considered was "*violent or unnatural*".

2025 Draft letter from Dr McCormick to Michael Burgess 29 June 1995 pp53-57 WITN7591020. The initial holding reply is at p15. No final reply after the draft has been identified.

cause of death. In contrast to the earlier advice the Department of Health wrote: *“On the death certificate there is a Box B on the reverse, which is usually initialled by the doctor, to alert the Registrar General that the doctor ‘may be in a position later on to give, on application by the Registrar General, additional information’. The doctor usually initials this box if he/she does not wish the HIV diagnosis to be recorded on the death certificate.”* The answers to the GP’s specific questions included:

- *“As regards the death certificate not giving correct factual information for statistical/epidemiological reasons – the information may be given later on application by the Registrar General. Also there is a voluntary HIV/AIDS clinician-reporting scheme to the PHLS,<sup>2026</sup> which has proved effective.”*
- *“The specific diagnosis of HIV/AIDS does not have to be revealed. Indeed ... the GMC guidance booklet Confidentiality makes clear, **a patient’s death does not, of itself, release a doctor from the obligation to maintain confidentiality.**”<sup>2027</sup>*

In 2004, the Office for National Statistics wrote to Her Majesty’s (“HM”) Coroner for Inner London North who had asked about the recommended practice for completing death certificates. After setting out the legal position, the letter stated: *“Clinicians have also used box B to provide further details about the cause of death where they wish to preserve patient confidentiality. The practice has been accepted in these circumstances because the alternative may be that information about conditions such as HIV would not be provided at all.”* The letter was copied to EAGA.<sup>2028</sup>

The letter also described an attempt to reform the death certification process which did not proceed beyond initial consideration by the Parliamentary Select Committee:

*“A draft Regulatory Reform Order containing proposals for civil registration reform was laid before Parliament on 22 July 2004. The Order includes proposals to restrict access to information about cause of death. Currently the only certificate available following the registration of a death includes cause of death. Once the law is amended, agencies that need only evidence of the fact of death – for example to change tenancy, prove a will etc. – will not be entitled to see the cause of death. Families will be able to obtain a ‘short’ death certificate that omits cause of death details or agencies will be able to have electronic confirmation of death without cause. This change may help to resolve issues about patient confidentiality which concern clinicians.”<sup>2029</sup>*

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2026 Public Health Laboratory Service.

2027 Letter from Dr Mark Evans to R Clifford 4 December 2000 DHSC0032190\_084. The position on confidentiality was also recorded in an attached CMO letter from March 1988 about information to undertakers: “Although in the interests of confidentiality the exact nature of the infection should not be revealed by a doctor”. Letter from Department of Health and Social Security to All Medical Officers March 1988 DHSC0032190\_085

2028 Letter from Len Cook to Dr Andrew Reid 28 July 2004 DHSC0006453\_064

2029 Letter from Len Cook to Dr Andrew Reid 28 July 2004 p1 DHSC0006453\_064. The Select Committee on Delegated Powers and Regulatory Reform reported that the proposal was not an appropriate subject for a regulatory reform order. House of Lords Delegated Powers and Regulatory Reform

While in some cases the motives for not including HIV or hepatitis on a death certificate were well intentioned, they were also often deeply paternalistic. For families who wanted HIV or hepatitis to be included on the death certificate, and indeed the connection to the treatment with blood or blood products, the failure to give full and accurate information was fundamentally wrong. It is unclear why a system, such as that suggested by G Harrison,<sup>2030</sup> was not introduced whereby the true cause of death was recorded but the public record, or at least the certificate required to be used by the family, kept the cause of death confidential.

### Disparities in coronial practices

Until 2013, when the role of Chief Coroner was introduced for England and Wales, the practices of individual coroners had no oversight. There was a Coroners' Society of England and Wales, but this is an unincorporated association whose objectives include the promotion of the usefulness of the office of coroner to the public and the protection of the rights and interests of coroners. It *“does not issue guidance but newsletters, law sheets, circulars and guidance have been issued from time to time by the government department with coroner policy.”* They issued no advice to members.<sup>2031</sup> A retired coroner who had held coronial office for 37 years stated that *“I have no recollection of any death being referred which might possibly be within the scope of this inquiry and I do not recall it ever being raised by members or at Council meetings!”*<sup>2032</sup>

These issues of lack of oversight and lack of consistency in approach are captured by a letter written on 31 October 1995 sent from the Home Office to the NHS Executive about the approach of HM Coroner Richard Van Oppen in Exeter in holding inquests into all AIDS-related deaths, irrespective of the route of infection:

*“As I think you are aware, the general position is that coroners are independent judicial officers, and, subject to any guidance or determination on the matter by a superior court, it is entirely a matter for an individual coroner to decide what an ‘unnatural’ death is for the purposes of section 8 of the Coroners Act 1988 ... Although it would be perfectly possible for this Department to hold a different view about the interpretation of ‘unnatural’ in this context (not that we have so far sought the views of our lawyers), I am afraid that, even if we did, we would have no powers to require the Exeter or any other coroner to take the same view. I appreciate, of course, that a lack of consistency in these matters can give rise to real problems, but, short of legislation, or a test case, our powers are limited ... the issue has been discussed with experienced coroners from within the service. They considered that Mr Van Oppen’s views did not reflect the view*

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Committee Proposal for the draft Regulatory Reform (Registration of Births and Deaths) (England and Wales) Order 2004 14 December 2004 RLIT0002234

2030 Letter from G Harrison to W Jenkins 5 October 1989 pp1-2 MOJU0000013\_057

2031 Written Statement of Andre Rebello para 3, para 19, para 8 WITN7210001

2032 Written Statement of Andre Rebello para 9 WITN7210001. Michael Burgess was Honorary Secretary of the Coroners' Society 1991-2003.

*of the majority of coroners, although it might be shared by a small number of other coroners.”<sup>2033</sup>*

It appears nonetheless that some coroners sought, and would have welcomed, guidance on how to deal with inquests concerning infected blood and blood products: Dr Richard Whittington, HM Coroner in Birmingham, wrote to the deceased’s widow after an inquest he held on 8 December 1989 expressing concern about press attention suffered by the family.<sup>2034</sup> He also wrote to a clinician on 19 December 1989 about the same inquest saying:

*“Enquiries with coroner colleagues reveal that there is a varying attitude to these unfortunate cases and some coroners hold inquests and some do not. I have therefore written to Doctor John Burton who is the secretary of the Coroner’s Society suggesting that he co-ordinates a policy now that Mr. Justice Ognall’s tribunal has been set up to ensure that coroner’s [sic] treat these cases as Death by Natural Causes and no inquest is held.”<sup>2035</sup>*

However, no central guidance was provided, and the lack of it meant that a wide variety of practice was followed in the different areas.<sup>2036</sup>

In Oxfordshire HM Coroner Nicholas Gardiner took the view that he was required to undertake an inquest in all cases of deaths from infected blood because they were “unnatural” deaths. He wrote to Dr Charles Rizza, director of the Oxford Haemophilia Centre, on 17 April 1989:

*“Further to our telephone conversation I did write to the Secretary of the Coroner’s Society and he confirms my own view that there is no easy answer to the problem. I understand that the Registrar General has issued general instructions to Registrars of Death that if the infection appears on the Doctor’s certificate they should not enquire how it was caught. For this amongst other reasons only a very small number of cases are likely to be reported to me at all ... Under Section 8 of the Coroner’s Act 1988 where a Coroner is informed that there is a body in his district and there is reasonable cause to suspect that the deceased died an unnatural death then he shall hold an Inquest. ‘Unnatural’ is not capable of exact definition ... However, it is difficult to regard a transfusion as a natural process and if as in these cases I am told that a person was infected with H.I.V. as a result of a transfusion with a contaminated product and dies as a result of the infection I think I am bound to fulfil my statutory function. In essence it is difficult*

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2033 Richard Van Oppen was president of the Coroners’ Society. Letter from R Clifford to G Skinner 31 October 1995 pp1-2 DHSC0006199\_025. See also: Letter from Sue Inglis to Dr Christine Swinson 2 March 1995 DHSC0006199\_018, Letter from Hilary Curtis to Professor Kenneth Calman 7 September 1995 DHSC0006199\_030, Memo from Dr Swinson to Ms Dartnall 3 November 1995 DHSC0006199\_027

2034 Letter from Dr Whittington to Anon 8 December 1989 CRBI0000001\_025

2035 Letter from HM Coroner to Professor Alistair Geddes 19 December 1989 CRBI0000001\_017. The Inquiry has been unable to identify the letter to Dr Burton.

2036 The different approaches of a selection of regions can be found in Counsel Presentation on the Registration of Death and the Coronial System December 2022 INQY0000421



*to distinguish such a case from a case where a person for whatever reason is given the wrong drug and dies as a result.”*<sup>2037</sup>

In Manchester, HM Coroner Leonard Gorodkin, took a similar view, writing to Dr Hay on 22 May 2000:

*“It is correct that I will be holding an Inquest, not because there is any doubt about the cause of death. But because the underlying cause appears to be unnatural. Your opening sentence states that the reason for HIV was acquired from blood product treatment in the early 1980s. It is this that makes the death from an unnatural cause. I agree that nothing new will be learned from the process, and that the family may well be upset. Neither of those are reasons for not holding an Inquest and in due course when I have all the information I will proceed to Inquest.”*<sup>2038</sup>

Then, in April 2001, it was reported to the trustees of the Macfarlane Trust that:

*“whereas in the past there had been guidance from the Westminster Coroner, Paul Knapman, to the effect that Coroners Inquests for people with haemophilia and HIV were no longer necessary, it appeared that there had been a recent change of view on this subject. At least 6 inquests had taken place following such deaths in the past year. In a number of cases a verdict of ‘misadventure’ had been recorded and the Coroner had, on two occasion[s], mentioned ‘negligence’. Coroners Inquests caused families great suffering. Publicity, particularly where the death was of somebody living in a small community, could be devastating.”*<sup>2039</sup>

Differences in practice between coroners are also evident in a number of the haemophilia reference centre directors’ meeting minutes and documents.

In early 1986, Dr Peter Jones delivered a paper to a conference in Newcastle, in which he argued that:

*“The final vestige of confidentiality, and because of an insensitive response by the media, the privacy and dignity of affected haemophilic families is stripped away shortly after death by the decision of the Coroners’ Society<sup>2040</sup> to submit all cases to public inquest. Whilst I cannot, especially as the prescribing doctor,*

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2037 Letter from Nicholas Gardiner to Dr Rizza 17 April 1989 p1 OXUH0001262\_007. The Inquiry has been unable to identify the correspondence and instructions described. Written Statement of Mark Flynn paras 3.1-3.2 WITN7591001

2038 Letter from Leonard Gorodkin to Dr Hay 22 May 2000 p41 CRMA0000023. In his statement to the Inquiry, Mark Flynn, for the General Register Office, states that during the relevant period “A death from infected blood would be, and would have been, considered to be unnatural and therefore requiring referral to a coroner.” Written Statement of Mark Flynn para 11.5 WITN7591015

2039 Minutes of Macfarlane Trust meeting 24 April 2001 p8 MACF0000006\_003

2040 The Inquiry has been unable to identify any note of such a decision of the Coroners’ Society.

*argue against the fact that death from AIDS contracted via haemophilia treatment is misadventure, I do question the concurrent need for personal publicity.”*<sup>2041</sup>

Soon afterwards, Dr Jones gave evidence at an inquest in 1986 which reached a verdict of natural causes; Dr Jones welcomed this as likely to reduce the need for inquests to be held in similar deaths in future.<sup>2042</sup> He wrote to reference centre directors following the inquest:

*“I thought that you would like to have some good news for a change. As a result of great help from the Medical Defence Union and discussions with the Coroners Society, our local Coroner has now taken the decision that he will not need to hold an open inquest on every AIDS-related death. This week he returned a verdict of natural causes on a 62 year old man who died as a result of AIDS and cirrhosis. We still have two further inquests (both lymphomas) which have already been opened and adjourned to get through, but after that we should be able to preserve the anonymity of the families.”*<sup>2043</sup>

Dr Peter Hamilton has given evidence to this Inquiry that:

*“Because of the considerable stigmatisation of patients with Haemophilia and acutely in those with HIV and its association in the public mind with Homosexuality it is my recollection that Dr Jones had come to an accommodation with the Newcastle Coroner to refrain from writing HIV/AIDS on the Death Certificate ... Not all coroners allowed this practice without discussion. On one occasion it took some persuasion I remember not to open an inquest into the death.”*<sup>2044</sup>

On 13 February 1989, at a haemophilia reference centre directors’ meeting, the minutes record that: *“Professor Bloom felt that clear guidelines should be established regarding referrals to the Coroner. In Wales all transfusion-related HIV cases must be referred to him. This action is not general throughout the UK.”*<sup>2045</sup>

On 4 February 1991 the AIDS group of haemophilia centre directors were informed that:

*“Professor Bloom ... had a very good rapport with the local coroner who did not hold inquests but he had been dismayed to get a phone call from another part of Wales from a patient’s widow when an inquest was being held. He thought that this matter should be discussed by the AIDS Group Members. Dr [Margaret]*

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2041 Letter from Dr Jones to colleagues enclosing a paper titled AIDS and Haemophilia 17 February 1986 pp13-14 DHSC0002169. This paper included the following: *“in December 1982 the first case that linked AIDS and blood transfusion directly was reported and this, together with further reports of AIDS in haemophiliacs, proved without doubt that the disease appearing in haemophilia was essentially the same as that affecting the other risk groups”* and ended with the words: *“Watching the advent and unfolding of AIDS in the haemophilic population is like watching a slow Aberfan – the engulfing of a generation because we, as a country, did not act in time.”* Letter from Dr Jones to colleagues enclosing a paper titled AIDS and Haemophilia 17 February 1986 p5, p14 DHSC0002169

2042 The Journal *AIDS death verdict may help families* 3 April 1986 HSOC0015461, Evening Chronicle *AIDS inquest and Verdict in AIDS-link death case* 29 April 1986 HSOC0015477

2043 Letter from Dr Jones to colleagues 1 May 1986 HCDO0000271\_074

2044 Written Statement of Dr Peter Hamilton para 99.1 WITN4197005

2045 Minutes of Haemophila Reference Centre Directors meeting 13 February 1989 p3 HCDO0000432

*Swinburne said that in Leeds no inquests were held and there was no need to report AIDS deaths to the coroner. Dr Jones said things were satisfactory now but it used to be a horrendous situation. Professor Bloom said he was particularly concerned about the situation with small Haemophilia Centres. Dr Mayne said the Group should keep the situation under review and if a problem developed then further action could be taken.”*<sup>2046</sup>

On 16 September 1991 at a meeting of the UK Regional Haemophilia Centre Directors Committee:

*“Dr Savidge asked how many deaths go to the coroners court; he had several enquiries about this from Centres in his Region and he thought that there should be a Regional Centre Directors policy ... Dr Rizza pointed out that it depended on what was written on the death certificate as to whether or not there was necessity for the case to be referred to the Coroner ... Dr Hay said that there had been some problems with bereaved relatives who were keen that HIV should not be mentioned on the death certificate even though the death was HIV-related and he would appreciate guidance about this. Dr Wensley said that the Manchester Coroner wished to know if a death was HIV-related. He was strict on this point and as a consequence all of the Manchester cases had autopsies. The press was usually at the Inquest and it was reported in the local papers. Professor Bloom said that the Coroner in his region insisted on being told and on holding an inquest but there was no publicity.”*<sup>2047</sup>

In Scotland, no FAIs were held into deaths caused by infected blood and blood products.<sup>2048</sup> Judicial reviews were brought before the Scottish courts in respect of this failure, which were upheld, resulting in the Penrose Inquiry being established.<sup>2049</sup>

Campaigners in England were inspired by this to seek an Article 2 inquest but Joseph Peaty told the Inquiry: *“It felt like David vs Goliath, the battle was with the entire system and the family were not being listened to.”*<sup>2050</sup> The inquest was into the death of Stuart Fuller who was infected with HIV and Hepatitis C through infected blood products. The senior coroner

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2046 Minutes of Haemophilia Centre Directors AIDS Group meeting 4 February 1991 pp2-3 HCDO0000539

2047 Minutes of UK Regional Haemophilia Centre Directors Committee meeting 16 September 1991 pp7-8 HCDO0000441

2048 Counsel Presentation on the Registration of Death and the Coronial System December 2022 p56 INQY0000421

2049 Memo from Andy Shanks advising ministers on the establishment of public inquiry handling of additional deaths 9 January 2009 COPF0000101, Opinion of Lord Donald Mackay on petitions by Anon and Anon for judicial review of Lord Advocate and Scottish Ministers decisions 5 February 2008 DHSC5040661

2050 Written Statement of Joseph Peaty para 172 WITN4607031. The Department of Health made detailed submissions to the coroner arguing that most of the key conclusions of the Penrose Report were directly applicable to England and Wales, that the wider systemic issues relevant to Stuart Fuller's death had been fully addressed by the Penrose Inquiry and that there was *“no useful purpose to be served by a further investigation, whether by way of an inquest or a statutory inquiry, into the same issues.”* Submissions on behalf of the Department of Health 9 October 2015 p7, p15 WITN7690022. The coroner accepted this submission. Inquest Touching the Death of Stuart Fuller 11 April 2016 p9 WITN7690030

took time to accept that Article 2 was engaged and then: *“Once the Department of Health were invited to become party to the inquest it was noticeable that the long-held government line of ‘the risks were not known and benefits of treatment far outweighed any risk’ became the prominent view.”*<sup>2051</sup> It featured in the narrative verdict:

*“the HIV infection resulted from the administration of imported blood products from the United States of America administered between June 1981 and April 1982. At the time that the blood products were given to him the risks of infection were not known and the benefit of such products far outweighed the risks of infection. The circumstances of the use and contamination of the blood products were dealt with fully in the Penrose Report following a public inquiry under the Inquiries Act 2005 published in March 2015.”*<sup>2052</sup>

Joseph Peaty told the Inquiry: *“We were all disappointed with the outcome of the inquest which we felt had failed to identify the reasons behind why Stuart had received infected blood products. Stuart’s family had been through a gruelling, emotionally distressing time because of the delays and lack of urgency shown by the coroner, and having been alongside them the entire journey I felt emotionally drained and very disillusioned with the system.”*<sup>2053</sup>

By contrast, an inquest into the death of Steve Dymond, who died in December 2018, concluded in October 2022. For his widow, Su Gorman, it was a matter of considerable importance that the coroner recorded the medical cause of Steve’s death as *“1c Hepatitis C Infection Acquired from a contaminated blood product”* on the record of the inquest.<sup>2054</sup> The coroner explored the circumstances of his death and reached a narrative conclusion which noted that:

*“As a result of the infection with hepatitis C he suffered a variety of mental and physical symptoms which impacted on his university education, his career, his marriage and his ability to have children. There was little or no support available and the stigma of the virus created isolation, frustration and sadness at the loss of a life imagined ... Stephen Dymond’s death is the direct consequence of being given Factor VIII between 1976-1984 which was contaminated with hepatitis C”*.<sup>2055</sup>

## Difficulties within the coronial process

For families, engagement with a coroner was often distressing. Sarah Gough records that when her father died of AIDS, they were visited by the coroner’s officer that day:

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2051 Written Statement of Joseph Peaty para 174 WITN4607031

2052 Narrative Verdict for Stuart Fuller p43 CRMK00000001

2053 Written Statement of Joseph Peaty para 175 WITN4607031

2054 Written Statement of Su Gorman para 3 WITN2753006, Record of Inquest of Stephen Dymond 24 October 2022 p1 WITN2753007, Private Eye *Tainted Blood Scandal: Dymond legacy* 16 November 2022 WITN2753010. Since giving her statement, Su has died.

2055 Record of Inquest of Stephen Dymond 24 October 2022 p1 WITN2753007

*“because there was concern about what to put on my father’s death certificate. As he had contracted HIV via contaminated Factor VIII there was a suggestion that he had been unlawfully killed and we were told there would need to be an inquest ... Following discussions between our GP, the Coroner and the Churchill Hospital it was decided that the death certificate should read:*

- 1a Cerebral Lymphoma*
- 2 Haemophilia*

*This meant that AIDS was not even mentioned on the death certificate even though this was what led to my father’s death. It was very distressing for us, as a family, to have to go through this process when we were grieving.”*<sup>2056</sup>

Carol Betts describes that after her brother John’s death from HIV she *“was told that I couldn’t collect the certificate straight after his death because they hadn’t decided what to put on it. Eventually [the] Coroner’s Office called to say that they had put [bronchopneumonia] instead of HIV, apparently to avoid the stigma associated with HIV.”*<sup>2057</sup>

The process of an inquest was deeply traumatic for many families. One woman describes that:

*“There was an inquest into [my husband’s] death, which I did not want to be a part of because I couldn’t face going through it all so soon after his death and I worried about the press finding out his HIV status. Despite this, I was summonsed to give evidence at the inquest and was made to attend. I was told by the coroner that the inquest would start at 1:30pm but the press wouldn’t be there until 2:00pm, so I could get my part done before they arrived. However, when I arrived at the inquest the press were already there. The coroner told me to leave through the side door at the end of the hearing so that I could try and avoid the press. The next day I had a knock on the door from a journalist from the [local paper]. Initially I denied that I was ... as I just wanted him to leave.”*<sup>2058</sup>

Another woman describes attending the Inquest into her husband’s death:

*“The hearing lasted 3 hours but felt much longer. The Inquest heard evidence that [my husband] had been using Factor VIII between 1979 and 1984. It was found that this [was] how he must have been infected with HIV. I was questioned very aggressively by the coroner who was very unpleasant to me and made me feel like I was a fool for not knowing various dates relating to [my husband’s] treatment. It was the most awful experience and it made me feel as though I was on trial for murdering [my husband]. The Inquest recorded [my husband’s] cause of death as ‘misadventure’ along with ‘septicaemia’, ‘Acquired immune deficiency’ and ‘Contaminated Factor VIII’. This was recorded on [my husband’s]*

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2056 Written Statement of Sarah Gough paras 32-34 WITN1246001

2057 Written Statement of Carol Betts paras 90-91 WITN0473001

2058 Written Statement of ANON paras 25-27 WITN1415001

*death certificate ... I cannot remember the reasons given for the finding of 'misadventure' but I found this finding deeply upsetting: it made it sound as though [my husband] was in some way responsible for his own death when the truth is that he, and all the other haemophiliacs who lost their lives, were killed by the wrongful use of infected blood products."*

When she got home from the inquest:

*"there were people from the press surrounding my house. I locked my door and wouldn't answer any questions but they continued to bang on my door and the back wall of the house. They then went around the neighbourhood, knocking on everybody's door on the street, asking 'Do you know you live next door to somebody who died of AIDS?'. I had to stay with my sister at the time as living in my house was not safe because of the press and because of the way that my neighbours reacted to the news that [my husband] had died of AIDS. The stigma surrounding the disease led to fear and isolation for me and my family."*<sup>2059</sup>

Other families could not understand why an inquest was required: *"His death was the subject of a post-mortem and a coroner's inquest, which took place on 5 September 2000. I've never understood why this was necessary though the post-mortem report ... comments, 'The likely cause of the Hepatitis C infection was multiple transfusions of FFP [fresh frozen plasma] (for hypogammaglobulinaemia). Therefore, for Inquest'."*<sup>2060</sup>

The delays caused by inquests could also be upsetting. Guy Dewdney says:

*"When my father passed away, the doctor gave us a 'white paper' to take to the Registry Office. When we received this we saw that the doctor had written that my father died as a result of being given contaminated blood. The registrar noticed this and said it would have to go to the Coroner's Court, but he was on holiday for the next 2-3 weeks. This meant we had to wait until after the Coroner returned to bury my father. This was very upsetting and something that still upsets me to this day."*<sup>2061</sup>

## Evidence relating to vCJD

Peter Buckland has given evidence to the Inquiry about the death of his son, Mark, from vCJD.<sup>2062</sup> An inquest in August 2006 reached a narrative verdict that: *"Mark Adam Buckland died as the result of infection with variant Creutzfeldt Jakob disease prion agent transmitted to him by transfusion of vCJD infected blood on surgery in September 1997"*.<sup>2063</sup> The coroner

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2059 Written Statement of ANON paras 31-35 WITN1537001

2060 Written Statement of ANON para 8 WITN0102001

2061 Written Statement of Guy Dewdney para 26 WITN1187001

2062 Written Statement of Peter Buckland WITN0694001, Peter Buckland Transcript 6 June 2019 INQY1000015

2063 Summing up of the Inquest into the death of Mark Buckland 16 August 2006 p7 WITN0694008, Letter from Arthur Hooper to Dr Patricia Hewitt 26 September 2006 p4 WITN0694002, Death Certificate of

recorded in his summing up that the blood service had been informed on 18 August 2000 that the blood donor, who had subsequently developed vCJD, had died and that Mark was not informed until 31 December 2003. He took note of the local neurologist's contention that as soon as the blood service and Department of Health became aware, the National Prion Clinic should have been informed and asked to contact Mark and his GP to offer expert assessment and advice.<sup>2064</sup>

The coroner said: *"During the hearing I referred to Rule 43 of the Coroner's Rules which allow a Coroner at an inquest to announce that he is reporting the matter to the relevant authority if he believes that action should have been taken to prevent the recurrence of a similar fatality ... Strictly, Rule 43 does not apply in Mr Buckland's case"*. Nevertheless he went on to say that he would be writing to the appropriate agencies: *"It is my view that in any event patients should have the opportunity of receiving appropriate assessments, advice and treatment if they wish and being able to deal with the possible future, doing what they wish to do and helping their families to come to terms with the future as well."*<sup>2065</sup> He wrote in these terms to the Secretary of State for Health.<sup>2066</sup>

## Commentary

A fatal accident or coronial investigation was, and is, usually the first time that those bereaved by a death have a review of the circumstances of the death conducted by someone independent, whose findings are likely to carry some weight with others, and whose views may contribute to others being spared a death from similar causes. It is of particular significance where the death may have been caused by failings of the state or by an organisation for which the state is centrally responsible.

It is clear that there were weaknesses in the system of death certification and investigation: in particular, it was said to be fragmented, not sufficiently professional, applied variable standards across the country, and did not satisfy the public interest in the discovery of the true causes of death in the population, nor contribute to the extent it should to the improvement of public health and safety.<sup>2067</sup> The system in England and Wales was said to

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Mark Buckland WITN0694006, Inquisition decision on the cause of death of Mark Buckland 20 May 2006 WITN0694009

2064 Summing up of the Inquest into the death of Mark Adam Buckland 16 August 2006 p2, p7 WITN0694008

2065 Summing up of the Inquest into the death of Mark Adam Buckland 16 August 2006 p6 WITN0694008

2066 Letter from Arthur Hooper to Dr Hewitt 26 September 2006 p4 WITN0694002. He wrote: *"I trust that the procedures that have been adopted in the past will now be reviewed and that other persons who may be at risk will be fully informed as soon as there is knowledge that risk has arisen, with advice to both him or her and their GP of the appropriate steps to take including, I would suggest, reference to the National Prion Clinic for assessment. Such an approach may be equally relevant to cases of transmission of possible infection in other contexts ... The relevant centre for assessment would of course depend on the nature of the risk."* Caroline Flint replied as Minister of State for Public Health and said that an expert group had been set up: *"As you have rightly pointed out, it is important that the patient be given choice so they can make that decision ... the emphasis must be on the patient or individual, who has been informed they are at risk. They must be allowed to make an informed choice."* Letter from Caroline Flint to Arthur Hooper 12 October 2006 p3 PRIU0000015

2067 See footnote 1922.

be unfit for a modern society without significant reforms.<sup>2068</sup> These weaknesses have been addressed, by the Shipman Inquiry and by a Fundamental Review in 2003 (in England and Wales) and by Lord Cullen in 2009 (in Scotland), and by legislation which followed in both jurisdictions.

Neither the system of certification or investigation was apt to provide data which would form a reliable base of information which might help to enhance public health, alert individuals to potential health threats, inform decisions as to the need to screen for particular viruses, or the like. It would be difficult to obtain much that was statistically useful from looking at the totality of death certificates produced during the 1970s and 1980s, and indeed into the 1990s, because of a lack of an agreed approach and of consistency in the descriptors used to reveal (or avoid revealing) that hepatitis or HIV infections were the underlying cause of the death. Trends, however, might have been discovered, but the discovery was always likely to be surrounded by uncertainties. It is unnecessary for this Inquiry to add its voice to that of the inquiries into deaths caused by Harold Shipman or Beverley Allitt or at Bristol Royal Infirmary, or to the conclusions of the Fundamental Review.

However, the evidence heard by this Inquiry in respect of death certification has shone a particular light on two matters. The first is the degree of paternalism by certifying doctors. Though the motives for mis-describing the condition which was the immediate cause of death, or the underlying one, may have been well-intentioned it would have been far better if this had been discussed with the bereaved. The fact that there were wide differences of view as to whether they wanted AIDS to be mentioned, or thought it the last thing they would want, highlight the importance of one of the points the Medical Ethics experts made to the Inquiry – that to respect the autonomy of the individual, the desires and values of that person need to be respected, and the first step towards doing that is to talk to them to understand what these are.<sup>2069</sup> This paternalism led to distress for some, and to a misunderstanding (in some cases) of the motives that led to it. It led people to wonder whether the mis-description of the illness was intended more to protect medical professionals than it was to benefit them. The Inquiry is left with a sense that many doctors may not have appreciated the importance of the wording of death certificates to the bereaved. The second point is to wonder why a system that allowed AIDS to be confidentially recorded was not established, if families did not want it on the public record, and to conclude that a means should have been implemented to ensure this.

As to investigations, the disparity in practice across England and Wales was a reflection of the way the coronial system operated generally. There is no evidence that this diversity of approach was specifically related to infected blood. However, the autonomous fiefdoms of coroners meant that determinations were unpredictable and often too dependent on local clinicians' relationships with the local coroner. Though, again, there is no criticism of what was

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2068 House of Commons Constitutional Affairs Committee *Reform of the coroners' system and death certification* 1 August 2006 p7 RLIT0002270

2069 Medical Ethics Expert Panel Transcript 26 January 2021 p29 INQY1000090, Expert Report to the Infected Blood Inquiry: Medical Ethics April 2020 p6 INQY0000241



probably well-intentioned, the Inquiry would have wished to see some evidence that these coroners consulted the representatives of families, which in the case of people with bleeding disorders formed easily identifiable groups that could have responded meaningfully to any approach. The disparate approach taken by coroners tended to close down another avenue whereby answers could be obtained – yet the system was intended to provide information to the bereaved which might provide answers, and to illuminate means of preventing similar events in future. Preventing the same happening again would only be made possible if in the first instance what had gone wrong in the first place was made public.

The disparities were less apparent in Scotland, though there was a wide discretion there too. Before Lord Cullen’s Inquiry report led to changes, the Lord Advocate had refused a FAI into the deaths of Eileen O’Hara and the Reverend David Black. A judicial review of that refusal led to the decision being “reduced” by the Court of Session. The respondents did not reclaim against the interlocutors which were issued.<sup>2070</sup>

The Penrose Inquiry which followed was in part the investigation into a fatal accident that had been sought in the judicial review.<sup>2071</sup>

This brief account makes it clear that in Scotland, where a FAI was discretionary, the procurator fiscal referred a decision to Crown Counsel, who exercised that discretion in consultation with the law officers of the Crown where appropriate. A decision reached at that level, ultimately under the supervision of the Lord Advocate, was reviewable by the Court of Session. The system thus provided in theory for a level of consistency and predictability absent in England and Wales for much of the time with which the Inquiry is concerned. However, a petition for judicial review was needed to bring the issues of infections resulting from infected blood products before an inquiry. It succeeded, and ultimately secured the investigation which had been sought. In having a system where ultimately a decision not to hold a FAI was that of the Court of Session on a petition for judicial review, it was little different from the position in England and Wales in respect of decisions not to hold inquests.<sup>2072</sup>

Though having recourse to the courts, in Scotland as in England, is a valuable safeguard, for those who were bereaved, who were disappointed by an early decision not to exercise discretion and hold an inquest or fatal accident inquiry, it must have seemed a daunting prospect.

In summary, the system was there to provide answers, to establish the prevalence of certain causes of death, and to inform better protection in the future. As it was, until well into this millennium, it proved an unreliable source of information, often hid rather than revealed causes of death, and did little to inform ways of protecting the public against any future blood-borne disease let alone continuing deaths from those that were currently in circulation. An opportunity was missed.

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2070 In English terms, they decided not to appeal.

2071 It was a specific term of reference. The Penrose Inquiry Final Report p13 PRSE0007002

2072 There have been a number of judicial review applications in England which have led to inquiries into deaths being held.

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