

# **SUMMARY OF CONSULTATION RESPONSES: TERMS OF REFERENCE FOR THE INFECTED BLOOD COMPENSATION STUDY**

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# **CONSULTATION REPORT**

## **Introduction**

The purpose of this Consultation Report is to summarise the public responses to the Infected Blood Compensation Study's public consultation on its Terms of Reference for the scope of its work in looking at options for a framework for compensation for the victims of the infected blood tragedy.

## **Background**

On the 25 March 2021, the Paymaster General made a Parliamentary statement announcing the Government's intention to appoint an independent reviewer to carry out a study to look at options for a framework for compensation, and to report back to the Paymaster General with recommendations before the Infected Blood Inquiry reports. The study would be entirely separate from the public inquiry, and would not seek to duplicate the work of the Inquiry or cut across its findings. The statement also confirmed that the terms of reference for this study would be finalised in consultation between the independent reviewer and those infected and affected.

On the 20 May 2021, the Paymaster General announced the appointment of Sir Robert Francis QC to undertake the role of independent reviewer for the Infected Blood Compensation Study. Sir Robert was tasked, drawing upon his legal expertise and experience in medical ethics and clinical negligence work, with providing the Paymaster General with advice on potential options for compensation framework design and solutions for consideration on publication of the Inquiry's report. Sir Robert would also draw upon his experience as counsel for interested parties at a number of public inquiries and as chairman of the Mid-Staffordshire NHS Foundation Trust Inquiries, the Freedom to Speak Up Review as well as three inquiries into the care and treatment of mental health service users who have committed homicide.

Draft Terms of Reference for the Study were published on 14 June 2021, and a public consultation exercise was launched seeking the views of the infected and affected, and others with an interest, on the suggested scope of the Study. The consultation in particular sought views on whether the seven bulleted points suggested covering the scope of the Study sufficiently captured all the issues that the Study should consider and whether there were other issues missing from the list.

## **Consultation Responses**

The Study's consultation did not seek responses to a series of formal questions, instead it asked for general views on the scope and focus of the Study's proposed undertaking. The consultation exercise received formal responses on the Terms of Reference from **447** individuals and representative groups. The Study also held a video conference meeting with the Haemophilia and Contaminated Blood All Party Parliamentary Group, at which a number of other representative groups were also present, to answer their questions and to hear their views on the Terms of Reference. Additionally, the Study received **152** further representations from the infected and affected, primarily personal stories, which while they offered no direct commentary on the Terms of Reference, provided a wealth of information on the infected and affected's personal experiences of this tragedy. Sir Robert is very appreciative of receiving all these responses, particularly given how difficult it must be for many respondents to replay these experiences often having done so more than once before. All of them will feed into the Study's work moving forward.

The Study has analysed the responses and extracted the key messages that were of most concern to respondents in relation to the Terms of Reference. A summary of these views, reflected against the seven draft Term of Reference (ToR) that were published on 14 June 2021, is set out below:

***“... My sister and I then realised that there was a real risk my Dad could have contracted HIV from my Mum. We had ... to ask my Dad if he had sex with my Mum after she had received the blood transfusion. This is not a question you would ever imagine a daughter having to ask her father ...”***

## **Rationale for Compensation**

*“To consider the rationale for such compensation.”*

Very few respondents (5%) touched directly on this issue, with the majority of commentary coming from the representative groups, as there is a clear underlying presumption amongst the infected and affected that this issue has already been exhaustively addressed and resolved. A few respondents questioned whether it was necessary for the Study to be asking this question, as if necessary at all, it was a matter best left to the main Inquiry.

However, a number of the representative groups generally recognised that the Study needed to take a step back to consider the basic presumptions that underpinned the rationale for compensation, in order to identify and have regard to the full scope of issues that needed to be addressed. They identified this as a fundamental scoping exercise, rather than retreading the footsteps of the main Inquiry.

There were also some questions raised by respondents about whether the rationale for compensation was the same across all the infected, and whether there needed to be some differentiation in rationales for compensation across the different categories of infected and affected who might be eligible for compensation. There were also questions about how the eventual findings of the Infected Blood Inquiry with regard to responsibility for this tragedy would affect the rationale for compensation.

## **Independent Advice to Government**

*“Give independent advice to the Government regarding the design of a workable and fair framework for compensation for individuals infected and affected.”*

It was generally welcomed by respondents, where touched upon at all (**3%** of respondents), that the Study was undertaking its work independently of the government. Some respondents considered this lent the Study greater legitimacy and that they would be more confident about accepting its recommendations. Many respondents were also very pleased by the wealth of relevant prior experience that Sir Robert’s appointment brought to the undertaking, which itself gave them significant confidence that the issues they regarded as important would be given due consideration.

***“... It is not acceptable to exclude those who do not meet criterias of being a particular family member for example parents, siblings or Carer. I am an affected niece. I lost, I suffered and am affected no less because I am a niece. The fact I am not a sibling does not mean I have been less impacted or I matter less or that I do not count because I do matter and what happened to us all does matter! I lost my uncle, ... we were brought up like siblings and lived together at times ...”***

## **Scope of Compensation**

*“To consider the scope of such compensation, and whether it should be extended beyond infected individuals and their partners, to include for example affected parents and children, either because of the impact of caring responsibilities or the effects of bereavement.”*

While the overall response to the consultation provided a wide range of views from and issues of concern for the infected and affected, one of the areas of the draft Terms of Reference that received the most consistent commentary from respondents (63% of responses) was regarding who should be eligible for compensation.

A small number of respondents preferred the scope of who should be covered by compensation to remain quite narrow (infected only or infected plus partner), which was usually because a wider coverage did not match their personal circumstances or they felt that a line needed to be drawn somewhere for affordability and equity reasons, and that a wider pool of claimants would stretch any potential pot of funding too thinly.

However, the vast majority of respondents felt strongly that the net for eligibility for compensation should be cast much wider than it is currently defined. While there was some variation on exactly how wide the boundaries for eligibility should be drawn, a significant percentage of respondents focused on a core group they felt should definitely be covered: the infected themselves; their partners (including widows and widowers); parents who had lost children to the tragedy; children who had lost a parent or parents. Beyond this core, there were a number of other categories that respondents thought worthy of inclusion, including the children (particularly young children) of still living infected, siblings of the infected, separated or divorced partners of the infected (particularly where they were major carers for the infected for a significant period of time), and significant wider-family or non-family carers. A question was also raised about the potential relevance of the provision in the law of Scotland entitling a wider range of relatives to damages in civil actions.

A small, but not insignificant, number of respondents, while agreeing that compensation should be spread wider than at present, thought that for simplicity and equity of administration purposes, compensation amounts should be given in their entirety to the infected or their estates (if deceased) and that it should then be for the infected and their estates to divide the compensation amongst their family and others as they saw fit.

Many respondents (**61%**) also offered comments on the scope of the Study in terms of what issues they thought a compensation scheme should address (i.e. the nature of compensation). This area was a primary focus for respondents (after who should be eligible) and one upon which many of them had given considerable thought. Respondents felt that the Terms of Reference should allow consideration of a number of key themes which recurred throughout these responses:

- the most consistent theme amongst the vast majority of those who responded, was that it was imperative that compensation should not just address the physical cost of infection, but also needed to take account of a range of other factors, including the injury to mental health, stress, social and relationship factors, the stigma associated with infection and financial loss (both the real loss of earnings and pensions and in terms of loss of opportunity) to both the infected, their primary carers and families;
- many respondents felt strongly that any compensation process needed to address the significant, and often long-term, side effects (such as liver damage, increased risk of cancer, diabetes, etc.) on many infected of the medication treatment regimes they underwent, particularly as these were often extremely stressful and painful (often more so than their illness itself) and in many cases (particularly the early treatment regimes) ultimately unsuccessful;
- respondents were keen for the Study to look at the potential impact of paying compensation, particularly large lump sums, on other state-provided income streams (other than the current support schemes), such as benefit eligibility (disability, Universal Credit, tax credits, etc.) and pensions, and for the Study to consider options for reducing disruption to either payment of or eligibility for these other systems;
- likewise, many respondents were keen for the Study to also consider the potential impact of the various current taxation systems on both how compensation was paid, and how recipients intended to spend (or save) such compensation payments, in particular making lump sum payments tax free, the effects on income tax, and inheritance tax;

- there was considerable support for the framework either to provide financial compensation, or recommend the establishment of processes (potentially mandated through legislation) to support and assist the infected and affected in overcoming the perennial difficulties they experienced in obtaining life insurance, mortgages and travel insurance; and
- there were varying views expressed about the desirability of lump sum awards and periodical payments; and there were some respondents who favoured simplicity and swiftness which they saw could be achieved by a broad brush approach to entitlement over complexity and detailed individual assessment of losses and needs.

***“... I have tried to understand the comparable compensation framework in the [Republic of Ireland] and to be honest I can’t understand why one person has received €2.7M when the average is €450K (approx). No one has been hurt more than anyone else with the contaminated blood scandal, so I would strongly recommend that all victims are treated equally and fairly ...”***

## **Measures for Compensation**

*“To consider the measures for compensation, looking at other national schemes (for example, the compensation tribunal established in the Republic of Ireland).”*

A small but significant number of respondents (21%) commented on the draft ToR proposing that the Study look at the compensation schemes that had been implemented in other nations. As the Republic of Ireland scheme was specifically mentioned as an example in the ToR, the majority of responses focused on that scheme, however a number of other national schemes were also mentioned (Germany, France, Canada, Japan).

Of those respondents that commented specifically on the Republic of Ireland scheme, opinions were split fairly evenly on whether or not it would make a good model for a UK (or devolved nations) scheme. Respondents either supported or opposed the Irish scheme for very similar reasons focused around the tribunal nature of the scheme: those supporting it did so because it would take account of the specific circumstances and needs of individual infected and affected, and unfavourable outcomes could be legally challenged; those who were against it did so because it would involve the employment of lawyers, would be time consuming, cumbersome and expensive, would require victims to have to provide detailed proof of their circumstances, and they considered it unequitable (particularly because it was challengeable) because it would come down to how good your lawyers or your paperwork was - or how loudly or persuasively you shouted in your corner - and that inequality in awards would lead to further divisions within the community.

A small number of respondents thought it would be difficult to make comparisons with any other country’s scheme, given the differences in the legal and healthcare systems between nations.

## Relationship with Current Schemes

*“To consider the relationship between a compensation framework and the current financial support schemes.”*

The issue of the relationship between any compensation framework and the existing financial support schemes was an area on which a significant percentage of respondents expressed a view (**49%**). While a number of respondents considered compensation and the ongoing support schemes to be completely separate issues that should not be reviewed together, the significant majority of respondents on this issue acknowledged that the relationship needed consideration. There was, however, an overwhelming degree of support for ongoing support schemes to continue in some form in addition to any compensatory award, as well as some anxiety expressed that the introduction of a compensation scheme should not leave anyone worse off than they are now.

There was significant variation on respondents' views, generally flavoured by their own personal experiences, of the efficacy and value of the current support schemes. Many respondents were grateful for the vital day-to-day support in meeting their basic financial needs that the support schemes afforded to them. However, respondents were also very cognisant of the flaws and restrictions they regarded plagued the schemes as they were currently administered. These focused around a number of key themes:

- while affecting only a small number of infected and affected, the rigid adherence to the September 1991 infection cut-off date for eligibility for ongoing support was seen as a particularly unjust disservice to those infected who could trace their infection close to, but not prior to, this deadline;
- general uncertainty about ongoing parity issues between the various devolved schemes (both current and how that might look post-compensation framework), along with frustration at the slow pace of addressing these issues currently - an area that many respondents hoped a comprehensive review by the Study would address (irrespective of whether ultimately administered centrally or individually by the devolved authorities);
- in a similar vein to that touched upon above in the wider compensation eligibility, respondents were concerned that current support schemes only supported a narrow portion of the infected and affected community - the infected themselves and their current partners (including widows and widowers) - and needed to be much wider in their consideration of who required ongoing financial assistance, in particular those engaged in primary carer roles (irrespective of familial connection);

- concern amongst a number of the co-infected community that the current support schemes were not considering their particular needs equitably - which suggested a need for the rationale and mechanisms for calculating such support to be much more transparent and accessible;
- many respondents expressed frustration at the inconsistent coverage of the current support schemes - with many eligible infected missing out - due principally to the lack of availability of informed advice about the schemes and a dearth of accessible publicity material, which had resulted in many infected and affected being unaware that they might be eligible for support for many years; and
- uncertainty over whether the Government intended to guarantee ongoing payments for life (of either just the infected and/or their partner or estate), an issue which many respondents supported and upon which many held strong views.

***“... My sole wish now at 81 years old is that everything can be brought to a quick conclusion and payments made in time to still benefit those of us who have survived until now ...”***

## **Options for Administering the Scheme**

*“To consider options for administering the scheme.”*

Consideration by respondents (**57%** of respondents expressed some form of view) on the options for a compensation scheme’s administration focussed on both the potential mechanisms for delivery of financial compensation as well as potential non-financial deliverables. As above, a number of consistent key themes emerged from this commentary:

- there was a strong desire amongst respondents that whatever the Study’s final recommendations were regarding how a compensation framework should operation, it should ensure that the scheme would not leave anyone worse off than they currently were - particularly when taking account of the impact of receiving compensation on ongoing support schemes and/or other state benefit eligibility;
- the majority of respondents were keen to keep some sort of monthly support system ongoing additional to - or separate from - compensation, in order to continue to meet the day-to-day cost of living needs of the infected. Many also considered the existing support schemes as ideal delivery routes for the payment of any compensation packages, as many of the infected and affected were already registered with the schemes (reducing the need for application processes and proving eligibility);
- many respondents were looking for a system which avoided unnecessary complexity or was adversarial in nature, and which kept the need for application processes and paperwork to a minimum, particularly around the level of burden of proof and evidence of damage required - which was particularly important for a number of infected, many of whom currently miss out on any support (and therefore potentially also on compensation), because of lost, destroyed or insufficiently detailed paper trails;
- a significant number of respondents were keen for the framework to be sufficiently flexible as to be able to offer the infected and affected some form of choice, in order to match their particular needs, in how they received any compensation payments - whether as a single lump sum, or in regular payments (monthly or annual), or some form of mixture of the two; and

- many respondents endorsed the need for the compensation framework to offer a potential range of ongoing non-financial compensation support options, in particular providing ongoing psychological support and counselling for those infected and affected who needed it.

## **Reporting to Government by February 2022**

*“Submit to the Government its report and recommendations as quickly as possible and no later than the end of February 2022, to provide the Government with advice on potential options for compensation framework design.”*

This was a ToR upon which very few respondents commented directly (less than **4%**). A small number of those that commented were keen either for the Study to report earlier than February 2022 or for some form of interim compensation to be put in place immediately ahead of the Study’s main recommendations. A small number were concerned with the sequencing of the Study’s reporting process (to the Paymaster General and then into the main Inquiry), preferring instead for the main Inquiry to complete its deliberations and make recommendations (including on compensation) and then for the work of the Study to be undertaken. The majority, however, were content with the February 2022 deadline for reporting on the Study’s findings, so that Sir Robert’s recommendations could feed into and be considered by the main Inquiry before its final deliberations - however, quickly expediting a framework into practical implementation once the Inquiry was over was a key message from those respondents.

***“... I am supportive of a compensatory framework, only if the framework should allow for immediate and swift compensation as a priority mechanism. This is as opposed to a system that requires an in-depth detailing of evidence and medical records for each person claiming - I could imagine this being quite prolonged and distressing to all involved to only serve to delay/reduce payments or avoid them entirely should someone be unfortunate enough to lose their life while mid-process ...”***

## **Discussion and conclusions**

The consultation raised a number of important issues on how the Study should be conducted, and on the scope of the issues that it needed to address. The response was generally very supportive of the need to engage with the issues raised in the draft ToRs in a timely manner, and understanding of the breadth and complexity of the issues that needed to be explored by the Study.

### **Should the Study be considering the rationale for compensation?**

It has been suggested by some respondents that the Study should not consider the rationale for compensation as the Government has undertaken to pay compensation if the inquiry recommends it. Determining what, if any, are the rationales for compensation as opposed to the support already on offer, is a matter for Sir Brian Langstaff and the main Inquiry to determine. However, in order to establish what should be the subject of compensation, it will be necessary for the Study to consider the possible rationales for such compensation, including whether they may differ for different categories of infected and affected, and for different issues for which compensation might be awarded, and what effect a finding of the existence of such a rationale by the Inquiry should or could have on the nature and extent of any compensation scheme. As such, it is important that the Study has the flexibility to explore all of the thinking behind rationales for compensation, both generally and in the specific context of the infected blood tragedy. This flexibility will also allow the Study to give full consideration to **all** of the issues that were raised by the infected and affected community. Ultimately, however, any conclusions and recommendations made by the Study would be subject to scrutiny by and dependent upon the subsequent findings of Sir Brian's Inquiry.

### **Scope of eligibility for compensation**

Varying views were expressed with regard to who should be entitled to compensation over and above the infected community. While there was general insistence that spouses, partners, children and siblings who were indirectly affected should be able to recover compensation there was support for including other

categories of those who have suffered indirectly, including parents, grandparents, former spouses and partners, more remote relatives and people close to the infected who were not related at all. It should be clear that these are matters which it is open to the Study to consider.

***“... There were constant rumours and people asking me “what did Dad die from?”. I was told to never tell the truth of the matter. Do not get me wrong. I was never bullied, picked on or singled out. But I lived knowing that if the truth came out I would be ...”***

### **What should compensation cover?**

Not surprisingly, the vast majority of respondents to the consultation exercise had opinions on what any compensation framework should and should not include. At this stage in its work, the Study will look to keep its considerations on all of these potential areas as wide ranging as possible, and does not seek to limit - or appear to limit - the scope of its deliberations. That said, as has been outlined above, there are some key recurring themes that large numbers of infected and affected, and their representative groups, agree should be central to the Study’s investigations. These include consideration of injury to mental health and stress, social and relationship factors including the stigma associated with infection and the financial impacts of loss of capacity and opportunity to both the infected, their carers and family members. Additionally, the Study should also consider not just the direct effects of infection, but long term side effects such as organ damage and vulnerabilities in respect of future health.

However it is clear that there are a whole range of other issues, beyond the above, that the Study needs to consider, for example how to treat (for both compensation and ongoing support purposes) those for whom the infection cleared naturally or whether to include the ex-partners of the infected where they are no longer together but who were carers for a considerable period, and others for whom the impact of the illness of the infected had a serious impact on their own lives. It is, therefore, clearly important that the above worthwhile focus does not limit the Study’s consideration of any other potential areas of interest, and in particular does not seek to prematurely narrow or define the types of, scope of or eligibility for compensation options.

### **Single UK scheme vs. separate devolved schemes**

A key message from respondents is that they are looking for the Study to make recommendations for a compensation framework that addresses holistically the needs of **all** UK infected and affected, irrespective of whether the delivery of that

framework is managed centrally or individually by the devolved administrations. The infected and affected have made it clear that they are seeking a system which ensures and maintains parity regardless of where those affected might be physically located (or where their infection originated). To that end, it is important that the Study considers carefully the current differences in both the support systems and legal frameworks covering each of the devolved nations. It is equally important that the Study works closely with representatives of the devolved nations to understand the contexts within which they operate (both currently and historically), draw upon their experience of how current systems do (and do not) work effectively and take account of their views on how a future compensation framework might operate.

***“... I think they should separate the infected people in to different groups on evidence, and be done with it, everyone got infected through no fault of their own, they know this, myself I can’t prove it like a lot of other people, but so what - we did not get infected by someone with a unlucky magic wand, just because we have no evidence we should not be discriminated with the level of compensation, the whole case must cost a fortune and could have been paid to the victims instead ...”***

## **Legal issues**

As already referred to, respondents drew attention to the differing laws in the devolved nations with regard to support and entitlement to damages. The Study will have to consider these differences and how these might impact on any proposed scheme.

Some respondents were concerned about whether the new scheme would prejudice their rights to pursue legal action. Many objected to an earlier requirement to undertake not to bring legal action in return for benefits received. The Study will have to consider the relationship between any recommended scheme and the existing and potential future litigation.

The law presents a number of barriers to claims for damages for personal injury including time bars through expiry of limitation periods, remoteness of damage, the burden and standard of proof, proof of causation, and the obligation to mitigate loss. Respondents referred to some of these and questioned whether they should have any relevance in relation to entitlement to claim compensation under a scheme. It will be important for the Study to consider whether, and if so the extent to which, any of these and similar restrictions to entitlement should be relevant in any scheme.

Generally damages for personal injury can only be recovered on proof of negligence or other breach of a legal duty. An issue the Study will have to consider is the extent

to which compensation should be limited to those cases in which a breach of duty can be or has been established or whether there is a case for extending entitlement to compensation to all those who have suffered as a result of the use of infected blood or blood products regardless of fault or breach of duty.

## **Conclusion**

While there were a wide range of views expressed by respondents about both the Terms of Reference upon which the consultation exercise sought views and many of the specific issues that the Study would need to consider in its wider work, some clear messages and themes emerged that are helpful in informing revisions to the Study's Terms of Reference, as well as informing the Study's work moving forward.

Annexed to this report is an amended draft of the Terms of Reference originally published for consultation, which are intended to reflect the points arising out of the consultation discussed above where they could benefit from clarification or modification. These are only suggestions: to be clear the determination on the terms of reference remains a matter for the Government.

The strength of feeling some subjects elicited from many respondents is totally understandable. The impact of this tragedy on all those directly and indirectly affected is very clear and the Study will keep that firmly in mind as it proceeds with its work.