

DISCUSSION FORUM NOTE

Infected Blood Compensation Study (IBCS): Discussion Forum on Issues Affecting the Bereaved - Tuesday 2 November, 2021

Time: 2.30 pm - 6.00 pm

Attendance via Google Meet: Sir Robert Francis QC (IBCS); Amy Street (IBCS); David Kirkham (IBCS); 26 members of the infected and affected community that had expressed an interest in issues affecting the bereaved.

Introductions

1. Sir Robert welcomed all the attendees to the forum and thanked them for giving up their time to come and share their experiences and concerns with him on issues affecting bereaved members of the infected and affected community. He explained that the discussion was not being recorded, but that a general (anonymised) note of the meeting would be taken and published for public consumption.
2. Sir Robert went on to explain that he had read attendees' individual submissions to him, including those that had been submitted as part of the Study's terms of reference public consultation exercise, and where publicly available, had read their witness statements (and those of their families) that had been made to Sir Brian's Inquiry. He had not, however, had an opportunity to listen to or read the transcripts of any of their oral evidence to the Inquiry.
3. Sir Robert opened the discussion by acknowledging the tremendous ordeal that the community had been through, and explained that it was not his intention to protract that process in any way by overly prolonging the time it would take to undertake his Study. It was his job to strike a balance between completing his work relatively quickly, and ensuring he focussed in sufficient detail to allow him to fully consider all the key issues. He was, however, clear that any compensation scheme he proposed needed to be based upon the needs and experiences of those it was designed to serve. That required him to listen to what people wanted to happen with compensation and decide upon the best way to deliver that. That would not necessarily mean that everything that individuals wanted would become part of the scheme, but he was starting from a blank piece of paper not constrained by either current processes or legal definitions.
4. This particular forum was looking to bring together individuals who had shared a common experience - they had lost someone dear to them as a consequence of the infected blood tragedy. It would concentrate on what attendees thought needed to be addressed by compensation in order for it to meet the needs of the bereaved. While the questions posed in the recently published update statement were generic across the full study - and not just of interest to the bereaved - they would be a useful starting point for the meeting to consider.

Issues Discussed

Personal Experiences

5. A significant portion of the discussion forum consisted of attendees relating to Sir Robert their personal experiences, and those of their families, of living with and coping with their loved ones' infections and of the impact and consequences of their loved ones' deaths and the aftermath of that tragedy faced by the bereaved. This note will not seek to record or relay the details of those harrowing experiences, but will draw out some common threads and themes and how attendees saw those issues being reflected within the context of compensation.

Who Should be Entitled to Make a Claim?

6. While there was general consensus amongst attendees around the expected primary categories of beneficiaries for eligibility to receive compensation - infected, spouses and partners, parents, children, primary carers - there was a particular emphasis on ensuring that children of the infected were taken care of by the process, either by being eligible in their own right to receive direct compensation or by the estates of the deceased being able to make claims. Generally, all those who had suffered some form of loss, damage or detriment should probably be able to make some sort of claim, which could widen the scope to include siblings and others within close proximity. Sir Robert pointed out that generally the further away from the family group you got, the more difficult it might be to establish a moral entitlement - there would be a need to introduce a sense of proportionality.

7. There was a general feeling that came up a number of times across the discussion that there was a need to make it clearer that a deceased's estate could make a claim to compensation, certainly over the current processes in place across the existing support schemes. This was particularly important so as not to send the wrong messages and give the impression that the deceased and their estates were being disadvantaged. It should probably include estates being able to make a claim equivalent to one which the infected could have made if still alive, and which was separate from claims from the individually affected. There would also likely need to be some guidance on the scope of compensation claims where a claim was made by the donee of a power of attorney for an infected person who was still alive but who was not capable of representing themselves.

What Should Compensation Cover?

8. While some of the discussion attempted to answer the specific question of what should a bereaved person be able to claim compensation for, many of the issues raised would clearly overlap with discussion on wider issues within the Study on compensation coverage and would also be relevant to those still living with infection and their affected families. The areas highlighted included:

- **Pain and Suffering** - as generally recognised through damage and loss, not just for those who continued to live and suffer with infection, but also important to recognise the pain and suffering endured by those who had died (along with the fact that a life has been lost), and compensation to estates should include elements which cover that;
- **Grief** - while this covered grief in the conventional sense, which all bereaved have to cope with regardless of the reasons for their loved ones' deaths, attendees considered that there were some specific issues with regard to blood infection which accentuated that grief and made it harder to overcome. Those issues included: unauthorised post-mortems on their loved one's remains; many normal funerary processes not being undertaken as the family might have wished due to the potential or perceived risk of infection for funerary staff; losing multiple family members to the same cause;
- **Stigma** - the stigma of infection, both of the infected and those in regular close proximity to them, from the less informed - often including the wider family - which primarily arises from their own fear of infection, and subsequent attempts to reduce that stigma through secrecy, carries a heavy social and psychological toll throughout the lifetime of the infected (irrespective of whether they are subsequently cleared of their infection), and does not cease after the death of the infected but continues to affect their close relatives indefinitely;
- **Mental Health** - there were a number of overlapping and constant stresses that caused detrimental mental health issues for both the infected and their close family members, which included but also went beyond those mentioned above, such as the stress of financial uncertainty and poverty, the frustrations associated with brain fog and survivor's guilt. Attendees considered these were compounded by both the general lack of, and where it did occur the haphazard nature of, the availability of mental health support and treatment, and specifically a lack of providers who were both aware of and understood (and therefore could be tailored towards the needs of) the infected blood tragedy;
- **Treatment Side-effects** - many of the side-effects of treatment regimes undertaken to cure infection were physically and psychologically more gruelling, unrelenting and long-term damaging than the infection they were seeking to alleviate, and often resulted in wider knock-on effects such as loss of employment or education for the infected and/or their primary carer(s), as well as increasing the risk of other potentially terminal conditions, such as cirrhosis and cancer. These caused adverse effects not only for the infected person but for those close to them, and not infrequently witnessing the suffering added to the distress and sense of loss experienced by those close to the infected person.

9. A number of attendees quite strongly expressed the opinion that any compensation needed to contain a punitive element that addressed government and the health service liability in the infected blood tragedy, and that went hand-in-hand with an admission of that liability. For them a sense of justice prevailing and recognition that they had been made to wait a significant length of time for this outcome was an essential part of obtaining closure.

They considered that punitive damages were also important as a disincentive for ensuring that such a tragedy did not happen again. Others thought this might not be very likely to happen, and that recognition for responsibility was more likely to come through the findings of Sir Brian's Inquiry rather than through the compensation mechanisms.

10. As was the case with the response received from the terms of reference consultation exercise, there was a split of opinion amongst attendees as to whether their personal preference would be for a quick and low burden of proof system that allocated compensation equitably upon a tariff basis across a menu of eligible categories or for a detailed and intensive tribunal style system which took account of the individual needs and histories of applicants and made an individualised payment assessment based upon that evidence. Attendees generally agreed, however, that in order to cater for the wishes of the community as a whole, that some form of hybrid system would likely be needed which gave claimants a choice as to which route to pursue. One form of hybrid system suggested could be to pay a baseline tariffed sum across all categories below which no-one would fall, which could be administered quickly and allow some degree of financial security, and then allow for a claims process of individualised top-up assessments for those who considered they should be eligible for further compensation.

11. There was some discussion that personal preferences as to which route to take may fall very much along age lines - the older infected community don't necessarily have (or wish to commit) the time for a long process and may be content to opt for a quick tariff system, whereas the younger infected and affected community may feel they can take the longer, personalised assessment route.

12. It was suggested that one way to keep any claim system from being onerous could be to automatically transfer over data from the existing support schemes - if you were receiving support, you had already gone through the need to provide proof of eligibility - which would come with a presumption of compensation eligibility. Any claimants that were not currently on an existing scheme could register their interest before the Inquiry reported.

What Form Should Payment of Compensation Take?

13. There was a mix of views amongst attendees as to their personal preferences on how compensation should be paid: some would prefer a single lump sum, so that they could confidently make substantial financial commitments (such as the purchase of property), draw a line under the issue of compensation and not need to engage further with the issue going forward, and have a full compensation settlement in hand that could not be withdrawn or changed at a later date; some would prefer for ongoing (albeit significantly enhanced) regular payments for life, that would give a sense of ongoing financial security, without the uncertainties and risks of investing and managing a large single pot of money; and many would prefer some combination of the two approaches - an initial lump sum followed by a regular income.

14. While widows were already receiving some form of support (unlike children and parents), many were concerned about potentially losing what support they did receive, and were very keen to be given a sense of certainty as to their financial futures via some form of

guarantee as to the future of support payments. Some felt that it would also be helpful to have some form of clarity as to what exactly current support payments were for.

15. There was a general consensus amongst attendees that compensation should include ongoing non-financial forms of support. A lump sum would be less beneficial if it then needed to be spent mostly on carers or ongoing medical or psychological support. As mentioned above, there was a particularly strong view that some form of dedicated and specialised psychological support service was needed for the infected community. Some form of support or substitute for insurance systems (travel, life, health, mortgages) would also be helpful for the framework to consider, as well as some financial advice to assist those who receive lump sum compensation in how best to invest it. There was also mention of the potential for a memorial to commemorate the tragedy, which would need to be prominent in order for it to be meaningful - so that the public and politicians could not forget.