

DISCUSSION FORUM NOTE

Infected Blood Compensation Study (IBCS): Discussion Forum on Issues Affecting the Multiple Infected - Monday 29 November, 2021

Time: 1.00 pm - 4.00 pm

Attendance via Google Meet: Sir Robert Francis QC (IBCS); Amy Street (IBCS); David Kirkham (IBCS); 12 members of the infected and affected community that had expressed an interest in issues affecting those who had been multiply infected.

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 those not directly infected but otherwise significantly affected by blood infection. 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.
3. Sir Robert opened the discussion by acknowledging the tremendous ordeal that the community had been through, and emphasising that the aim of his Study was to make suitable recommendations to Government prior to the completion of Sir Brian's Inquiry, so as to ensure there was no significant delay in implementing a compensation scheme once the Inquiry had delivered its findings. He explained that it was his opinion that any proposed compensation scheme needed to be based upon the needs and experiences of those it was designed to serve, and that in designing such a scheme his starting point was to listen to the views of the infected and affected community - he was, in essence, starting from a blank sheet of paper.

Issues Discussed

Personal Experiences

4. 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 someone who had been infected through contaminated blood. 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?

5. Attendees felt it was important that any compensation scheme took into account those who were currently excluded from any type of support - parents, children, siblings, those currently unable to provide sufficient documentary evidence to meet current support criteria.

6. It was important that the estates of the infected, in particular children where they are still within the dependency of the family, were supported by compensation after the death of the infected. This is in addition to any compensation that would be due in their own right as affected. Where the infected was the primary provider (even if only through the support from the existing support schemes), it was important that such ongoing financial security continued.

7. It was also important to consider what date compensation might be payable from, as many infected had died decades ago, and there would be a need to be clear as to the eligibility of their estates to make claims.

What Should Compensation Cover?

8. As with other discussions, the conversation was wide ranging on what compensation should cover - and while there were some issues specific to the multiple infected, the underlying message was that compensation for the multiple infected should cover mostly similar territory to other affected groups, but with the acknowledgement that multiple infection generally accentuated these issues to a greater degree (for which some attendees argued quite strongly that individual infections should be treated separately for the purposes of compensation entitlement). Some of the general themes included:

- **Pain and Suffering** - all infected had had to live with immense pain and suffering, and core to any compensation should be recompense for this - this should be equivalent to the damages that would be covered under the heads of loss for any legal claim. Multiple infection often complicated the alleviation of such suffering, as treatments across infections were often not complementary to each other;
- **Treatment Side-Effects** - while most of those infected who attended the forum had experienced debilitating and damaging side-effects from the treatment of their infection, the treatment regimes for different infections often had similar side-effects (such as a reduction in bone density, increased liver toxicity or increased chance of cardiovascular events) which meant taking multiple treatments for multiple infections exponentially multiplied these issues, which in turn had an effect upon life expectancy;
- **Treating Infections Separately** - there was strong feeling amongst some that a compensation framework needed to treat multiple infections as separate entities when considering how to award appropriate recompense (essentially treating

compensation as a cumulative process for each infection suffered). It was important to avoid the multiple infected feeling they had been offered a 'reduced' settlement;

- **Mental Health** - compensation should recognise the high level of stress and detriment to general mental health that living with infection over an extended period of time has had on both the infected and those around them, not just from the physical debility itself but also from the financial instability and the stigma and stress of being treated like social pariahs;
- **Passage of Time** - compensation needed to recognise the significant length of time that the infected had had to live with the pain and suffering, and the stigma and abuse, before they had seen any likelihood of closure on this tragedy.

9. As in previous forums, a number of attendees felt quite strongly that there should be an element of exemplary and aggravated damages reflected within any compensation. This was particularly the case for those who considered that they had been infected when they didn't need to be (because either the risks were already well known at the time or because they felt they had been experimented upon and infected unnecessarily). It was also felt that the case for exemplary damages was particularly strong within the haemophilia community, which set it aside from the whole blood community which did not feel as strongly on the issue.

10. Sir Robert was asked whether he had been given any upper limit for compensation by the Government and whether he thought the Government saw a compensation framework as an economic limitation exercise. Sir Robert explained that, as befitting the nature of the independent role he had been appointed to undertake, he had been given little limitation on his considerations, and such as there were, these were set out quite clearly in the Study's terms of reference - he had not been given an upper limit to work within. He could not, however, speak for how the Government saw the work he was undertaking.

What Form Should Compensation Take?

11. Some attendees thought it important that any compensation scheme dealt equitably with everyone, and saw difficulties with trying to distinguish between individuals and groups. Fairness was key to both people accepting the scheme and to keeping it simple.

12. There was generally a leaning towards a simple tariff system (though one that compensated per infection) to keep the scheme fair and easy to implement. Attendees were generally less keen on individual assessments, which would be far too time consuming for some. However, it was acknowledged that some form of tribunal system would allow those who wanted to do so to quantify their individual loss and cover their unique circumstances. This tended to lean towards a hybrid system that had been raised in other discussion forums, where there was some degree of simple categorisation by different levels of harm that applied across the majority (these might need to be different than the current support scheme categories, which some felt were not very helpful in this regard, in particular not fully reflecting the seriousness and increase in mortality of the current Stage 2), and then those who were worst affected could pursue additional recompense.

13. Following any compensation payment for past damages, it was then important for there to be continuing regular support which recognised that the infected had not been able to develop careers or pensions, and which offered some degree of financial security for the future (beyond the compensation itself). It was also important that ongoing support came with a lifetime guarantee - this had happened in Scotland, and people had therefore managed to get mortgages on the back of this commitment. Attendees were generally keen for there to be consistency in the application of compensation payments and any ongoing financial support across the devolved nations, whether delivered by the existing support schemes or a national body.

14. It was important that any non-financial component to compensation included the provision of ongoing medical support, and in particular appropriate end of life and palliative care, which was currently very much lacking. As in previous meetings, there was general support for some form of healthcare passporting system, akin to the Republic of Ireland's Health Amendment Act card, which would allow priority treatment for the infected. Some form of advocacy service within the NHS, which proactively pursued problems on behalf of the infected, might also be a sensible option.

15. Attendees recognised that there would likely be a need for a compensation framework to include support and advice on financial management. Many of the people that could receive a large settlement were not used to dealing with large amounts of money, and many were vulnerable and not in a position to manage their own affairs. Some form of support would be needed to ensure that they were not taken advantage of. It was generally felt that this needed to be built into the scheme itself - rather than just including funds within a settlement to allow people to purchase their own advice - as many of the people who would most need that support, would be unlikely to seek it out themselves.

Other Issues

16. A number of attendees would like to see some exceptional circumstances, such as the tragic events at Treloar College, treated separately within a compensation scheme. In the case of Treloar, there was a feeling that staff were acting as stand-in parents and that there should have been an additional duty of care involved, and that events showed negligence in that duty. There had been a disconnect in the relationships between the on-site haemophilia centre and the Treloar College management, which should have worked more closely together but did not. There had also been a significant lack of information flowing out of the school to parents. There was a desire for some form of apology from the school and recognition of the problems this had caused. There was some recognition, however, that this might be beyond the boundaries of what the Study was looking at and might need to be addressed separately (such as through Sir Brian's Inquiry or pursuing separate litigation).