

## **DISCUSSION FORUM NOTE**

### **Infected Blood Compensation Study (IBCS): Discussion Forum for those Infected and Affected who were not able to attend a previous forum - Tuesday 14 December, 2021**

Time: 2.00 pm - 5.00 pm

Attendance via Google Meet: Sir Robert Francis QC (IBCS); David Kirkham (IBCS); 10 members of the infected and affected community that had been unable to attend one of the previously advertised discussion forums.

#### **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 the issue of infected blood. 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 he was starting from a blank sheet of paper and 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.

#### **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.

## What Should Compensation Cover?

5. As this discussion forum was not focussed around a particular topic, the themes raised by attendees on the issue of what compensation should be paid for covered the wide spectrum of issues that had been raised at all of the previous forum meetings. The areas highlighted included:

- **Loss of Earnings** - compensation should cover the loss of earnings and pensions suffered by both the infected and affected by having to pause or give up entirely their careers, and the accompanying loss of opportunity;
- **Length of Time** - need to acknowledge and compensate for the significant length of time that has passed with having to live with a debilitating condition, principally through any compensation being backdated to the date of an individual's infection;
- **Stress** - compensation needed to cover the extreme stress and anxiety that the infected and affected had to constantly live with: the stress of potentially infecting others; the impact of restricted familial and social relationships; of financial insecurity and their inability to effectively contribute to their families and society; of being told that painful and debilitating treatments might not work (or had not worked);
- **Missing Records** - any compensation framework needed a robust process for addressing the issue of missing or destroyed medical records and how claims from those with incomplete medical documentation would be sympathetically handled - ideally with the emphasis being on disproving a claim was valid rather than on claimants having to prove their case;
- **Claims by Estates** - any compensation framework needed to allow for claims to be made from the estates of those infected who had died or were incapable of claiming themselves, and these claims needed to be in addition to the ability for those affected to make claims on an individual basis;
- **Natural Clearers** - any compensation scheme needed to include those infected who had cleared their infection naturally from their bodies, and acknowledge that while they may no longer be directly infected, prior infection will have done physical harm (including long-term effects that may have not yet manifested) and have caused serious psychological damage and stress. For some this was particularly difficult to prove, due to lost or destroyed medical records, and scepticism from medical professionals - which added to the mental health burden. Many in such circumstances were currently not supported by the existing support schemes.

6. There was a dire need for ongoing medical and psychological support. There was currently very little or no counselling after treatment, and what psychological support there was did not cast its net wide enough (e.g. including the affected). The medical profession had no real idea how to manage and support the infected; there was a need for some strategic planning to remedy this deficiency. Look-back exercises had not happened early enough, and had missed many infected. There was a need for a new look-back exercise to

be undertaken and for it to be sufficiently wide to cover everyone who had received transfusions and to offer them the opportunity to be tested. The biggest outcome of this whole process should be the ability to produce lessons learned, in order to ensure this didn't happen again.

7. Consideration needed to be given on how long-term and palliative care would be funded and provided, so as not to be a stress and burden on the infected and their families (and eat up all of any compensation settlement).

### **What Form Should the Assessment Process Take?**

8. In line with previous discussion forums, and the wider response to the Study, there was a mixture of views as to the approach a compensation framework should take. There was support for both a quick and easy tariff-based scheme, and for a more in-depth tribunal style system which made individualised assessments. It was recognised that some form of hybrid system was likely to be the best approach in order to meet these diverse opinions. Whatever approach was taken, attendees were keen for the framework to be easy for the infected and affected to understand.

9. A number of attendees were keen for there to be some form of community representation within the decision making process of whatever system was adopted - particularly for a tribunal system, there was a desire for someone who had been through the illness to be able to act as a patient representative on any tribunal panel.

10. There was some concern as to whether a compensation framework would require legal representation in order to make a claim, as many had not currently sought - and were not particularly keen on seeking - legal representation. Keeping any system simple would hopefully preclude such a need.

### **What Form Should Payment of Compensation Take?**

11. There was a mixture of views amongst attendees on their preference for a single lump sum payment versus periodical payments, or some form of combination of the two. There was general consensus, however, that compensation needed to be generous and that previous payments - in particular the discretionary grant payments that had been received by those on the current support schemes - should not be taken into consideration and deducted from any compensation settlement.

12. As in previous meetings, attendees were very keen for the current support payment schemes to continue in some form (though they may need reforming), as they provided a sense of structure and financial security for those in receipt of payments. There was a desire for this support to be sufficient in nature to make the rest of the lives of those infected as comfortable as possible. There was support for treating any ongoing payments akin to a pension scheme, particularly as this might help in keeping the purpose of payments private and assist in providing anonymity for the infected.

13. As was being expressed elsewhere, attendees were keen for there to be serious consideration given to the possibility of at least some level of compensation to be paid before the end of Sir Brian's Inquiry, in the form of an interim payment.

### **Other Issues**

14. Sir Robert was asked how long he thought the Government might take to respond to his recommendations. Sir Robert explained that he could not say how long a formal response to his recommendations might take, as that was very much a question for the Government to answer. However, it was his understanding that the Government would look to respond in sufficient time for both the recommendations and the formal response to be put to, and considered by, Sir Brian Langstaff's Inquiry before it finished hearing evidence, which was likely to be towards the end of the Summer 2022.