

## **DISCUSSION FORUM NOTE**

### **Infected Blood Compensation Study (IBCS): Discussion Forum on Issues Affecting the Hepatitis C Infected - Monday 8 November, 2021**

Time: 10.00 am - 2.00 pm

Attendance via Google Meet: Sir Robert Francis QC (IBCS); Amy Street (IBCS); David Kirkham (IBCS); 20 members of the infected and affected community that had expressed an interest in issues affecting the Hepatitis C 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 infected with Hepatitis C. 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 - as any scheme which started and ended with lawyers would likely miss the essentials.

#### **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 and coping with infection with Hepatitis C. 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. There were a number of recurring themes raised by attendees on the issue of what compensation should be paid for - some of which were generally relevant to the wider discussion within the Study on compensation coverage, and some of which was specific to the needs of those infected with Hepatitis C. The areas highlighted included:

- **Pain and Suffering** - participants raised a wide range of injury suffered by themselves and others they knew including both physical and psychological damage and disability, for example liver inflammation, brain fog, fatigue, anxiety, depression, memory impairment, cirrhosis, cancer;
- **Stigma** - the stigma of infection, not just for the infected themselves, but also those in regular close proximity to them, encountered not just in familial and social circumstances (children bullied at school, extended family in denial and estranged, loss of friends), but also from medical practitioners (such as blood donations being labelled as a biohazard; being recorded as having positive infection on medical records, even after being cleared; being advised that it was better to tell people they had cancer; being told they are an expensive patient, because surgical equipment needed to be replaced; being categorised as drug abusers);
- **Treatment Side-effects** - many of the side-effects of treatment regimes undertaken to cure Hepatitis C infection were as physically debilitating and damaging, in many cases more so, than the infection they were seeking to alleviate, which was often exacerbated by the psychological effects of those treatments not working and potentially needing to be repeated, along with the financial and social costs of putting life on hold for a significant stretch of time to undergo treatment, together with the ever present fear of the threat of death;
- **Stress** - many infected were constantly afflicted by stress from the fear of passing on their infection (primarily to partners or children) and the impacts of that in restricting familial and social relationships;
- **Loss of Earnings** - having to pause or give up entirely careers, and the associated loss of earnings and pensions that accompanied that, not just for the infected themselves, but often also for their primary carers (which might include adult children as well as partners);
- **Unnecessarily Prolonged Process** - to compensate for the significant length of time that has passed with having to live with a debilitating condition without receiving much, if anything, in the way of formal recognition or support, and for many, without even being told of their infection for a very long after, in retrospect, they had started to suffer symptoms caused by the infection;
- **Lack of Consent** - many attendees considered that compensation should also cover the invasion of their autonomy, the psychological damage and general sense of

distrust in the medical system - which often had consequential effects, such as refusal of or indifference to seeking further medical support - that originated in the lack of informed choice and consent in the circumstances that led to or followed on from their infection (including being tested for infection and blood taken without knowledge, often over a prolonged period). Some believed they had been the subject of experiments without their knowledge. This had bred significant distrust and disappointment with the medical profession amongst some of the infected; medical practitioners were meant to do no harm, but there was a feeling that instead they had stuck together to cover their own backs rather than putting victims first.

6. While the primary focus of the meeting conversation was around Hepatitis C, as was the wider infected blood conversation (along with HIV), it was felt that compensation should acknowledge and cover all potential blood infections (Hepatitis A, B & D, vCJD, potentially others), which have generally received less attention. It would be an injustice if those suffering from other contaminated blood infections didn't also receive compensation.

7. As also mentioned in previous discussions, some attendees would like to see compensation contain a punitive element that addressed the issue of liability, and which might help convey a sense of justice to the process.

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

8. As with responses received by the wider Study, attendees had a mixture of views on whether they would prefer a tariff-based approach to categories of compensation, or whether they would look to a system based on individual assessments which took account of an individual infected's particular circumstances and needs. Some wanted a system which could be implemented easily and quickly, which did not require having to go through the process of making new claims or assessments, and which provided a degree of (generous) parity across all affected, in order to bring a quick sense of financial security and closure. Others, while recognising the benefits of a quick system (and generally being happy for such a process to form a baseline for an initial or interim payment), would prefer for their individual circumstances to receive some form of assessment to top up any initial settlement, not least because it would provide an opportunity to air their particular grievances and be heard, which they considered an essential part of achieving their own closure. Choice would be key to a scheme that could successfully meet these diverse needs.

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

9. As with previous discussions, there was a variety of individual preferences as to how compensation should be paid, whether by a lump sum payment or ongoing regular support or a mixture of the two. A scheme which allowed a degree of choice would be preferable. However, where a lump sum might be payable, it was generally agreed amongst attendees that it would be very helpful if there was some form of financial support in place for claimants, to help them manage that money effectively.

10. As had also been mentioned in a previous meeting, there was a desire for compensation to cover non-financial forms of support - in particular, an urgent need for a much expanded ongoing psychological support service which was aware of and tailored towards the needs of those affected by the infected blood tragedy. What psychological support was currently on offer varied considerably, and was invariably insufficient for the ongoing needs of victims and was inadequately funded.

11. Some form of ongoing specialised and targeted medical support should be available, possibly in the form of a fast-tracked passporting system that did not require the infected to have to wait on general treatment waiting lists - this would be particularly important for those infected whose Hepatitis C had caused more serious conditions such as cirrhosis or cancer, where significant medical intervention - such as organ transplants - might be needed. For many, this might be more important than purely financial compensation.

12. There was mention of the need to address the issue of difficulties the infected and affected had with obtaining life and travel insurance and mortgages.

### **Existing Support Schemes**

13. Many infected had for a long time been unaware of the support they could have been receiving, some even until very recently. There was poor communication of the support that was available - the lack of awareness of the history of the infected blood tragedy amongst medical practitioners also exacerbated this. There were also some infected, despite being aware of the schemes, that were still not receiving any form of support - mostly due to lack of medical records and evidence to prove the balance of probabilities of the cause of their infection. There was a general consensus that the current balance of probabilities assessments were too harsh and narrow and needed to shift more in favour of claimants, particularly where there was strong ancillary evidence (e.g. scars of surgery which would have definitely required transfusion).

14. Some attendees were also frustrated by repeated difficulties with proving eligibility for Hepatitis C Stage 2 payments from the schemes - this was particularly galling when they received conflicting advice and medical opinion as to their eligibility, and when evidence about the deterioration of their condition was questioned.

15. Opinion was split on whether attendees wanted the existing individual national support schemes to continue (although all wanted some form of ongoing support to continue) and to administer any compensation system - some had positive experiences of the existing systems, others less so.

### **Other Issues**

16. There was strong representation at the forum from the haemophiliac community, who were generally accepting of the risks and costs that this hereditary condition brought, but who were feeling let down by the medical profession for the additional burden that being given infected blood brought to already difficult lives. Those with bleeding disorders had a

greater chance of getting other types of infection, and in turn multiple infections increased the chance of cancer and liver damage. Additionally, the bleeding disorder community had multiple infusions, which increased their overall viral load. It was important for these additional complicating factors to be recognised.

17. Any compensation scheme needed to be aware of the particular circumstances that those infected who had cleared their Hepatitis C infection, either naturally or through treatment, found themselves in. While they outwardly may no longer show symptoms of infection, much long-term damage - some yet to show itself - had likely already been done to their bodies. The stress and worry of their infection coming back was also still constantly with them. Having been cleared physically of their infection, they often felt that medical practitioners then considered the job done and that they were no longer in need of attention (as exemplified by medical opinion offered to some that once an infection was out of someone's system, they should no longer experience side effects), which generally left them feeling further isolated from any support, particularly psychological support. It was untrue to say they had been permanently 'cured', and to think that they could just 'move on' with their lives.

18. Some attendees were keen on there being some form of acknowledgement and apology from either the Government and/or the medical profession in order to bring closure to the tragedy. A few felt that this did not necessarily have to involve allocating individual fault - something very general would probably suffice. There were differing opinions, however, as to whether this would fall sensibly within the scope of a compensation scheme or whether it would be better left for Sir Brian's Inquiry to consider.