

DISCUSSION FORUM NOTE

Infected Blood Compensation Study (IBCS): Discussion Forum on Issues Affecting the HIV Infected - Monday 15 November, 2021

Time: 11.00 am - 2.00 pm

Attendance via Google Meet: Sir Robert Francis QC (IBCS); Amy Street (IBCS); David Kirkham (IBCS); 3 members of the infected and affected community that had expressed an interest in issues affecting the HIV infected.

Introductions

1. Sir Robert welcomed 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 HIV. 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 explaining 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 he was starting with a blank sheet of paper - listening to the views of the infected and affected community was the first step in filling in that blank sheet. He acknowledged that this forum to discuss issues affecting those that had been infected with HIV, by the very nature of this devastating infection, was much smaller than previously held forums - but he hoped that that would allow more time to delve into the details.

Issues Discussed

Personal Experiences

4. Much 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 HIV. 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.

Changes to the Reporting Timeline of the Inquiry

5. It was noted that it had been informally reported in a number of meetings attended by the infected and affected community that Sir Brian's Infected Blood Inquiry anticipates it will now report its findings by the middle of 2023. Sir Robert was asked whether that decision would affect the deadline for producing his report on a compensation framework, as that short deadline now looked incongruous against the significant time gap before hearing Sir Brian's findings.

6. Sir Robert explained that the Study was aware of that suggestion, but it had not yet been announced formally by the Inquiry - and it had also not been formally conveyed to him. The deadline he had been given to make his recommendations, set by the Paymaster General in the Study's terms of reference, had been set when it was assumed that Sir Brian had been reporting in 2022. However, Sir Robert explained that he himself had been in similar circumstances when chairing inquiries and recognised that Sir Brian needed to allow himself sufficient time to deliberate and write his findings. This would not necessarily affect the point at which the Inquiry would wrap up hearing evidence, which could still be in the Summer 2022. As such, the deadline for making his recommendations on a compensation framework might not significantly change - he would report at the start of the Spring 2022, the Government would then take some time to consider his recommendations and formally respond, at which point he was likely to be asked by Sir Brian to give evidence to the Inquiry in the late Spring, allowing the Inquiry and the infected and affected community to respond to his recommendations before the evidence gathering section of the Inquiry wrapped up at the end of the Summer 2022.

[Note: since the forum meeting, on 17 November the Paymaster General announced a small extension to the deadline set out in the Study's Terms of Reference for Sir Robert to make his recommendations to the Government until the 14 March 2022, in order to allow for a further extension to the deadline for making written submission to the Study, which is now 19 December 2021.]

What Should Compensation Cover?

7. The recurring themes raised by attendees on the issue of what compensation should be paid for were very similar for the HIV infected as for other sectors of the community. While the discussion touched on a number of the areas which have come up more generally during the consultation process, there was a focus on two particular issues:

- **Treatment Side-effects** - while the treatment regimes for those infected with HIV were different than those for the Hepatitis C infected, they did share many of the issues experienced with debilitating and damaging side-effects of the drugs that were taken as part of those treatment regimes. HIV medication is known to reduce bone density (often exacerbated when also taken with medication for other conditions which can have a similar effect). There is, however, a general lack of research of the effects within the haemophilia community, particularly of the long-term consequences of living with comorbidities, which the Study could possibly look at;

- **Stigma** - infection with HIV has a significant and long-running societal stigma attached to it (partly fueled by the government health campaigns of the '80s and '90s) - and unlike many other conditions with which people are diagnosed, that stigma never goes away. Many went out of their way to keep their HIV infection secret for a very long time, and only recently has it become an issue that can be talked about with wider friends and family - but even now, there is still need to be careful on how widely it is known, so as not to have any stigma come back and affect other family members.

What Form Should the Assessment Process Take?

8. There was general agreement that some form of hybrid system was the most likely approach to take, with potentially a tariff system giving an initial settlement, followed by a tribunal-like system for those who additionally wanted their individual needs assessed. However, the biggest challenge with designing a framework was likely to be deciding what each group might get relative to another, and particularly the interrelationship between infections - there was a view amongst several attendees that the current process of separating victims into different categories had been corrosive for the community. This would require a lot of thought so as not to cause problems.

9. There was some discussion about how a compensation framework should treat cases where people no longer had medical records to offer proof of the details of the origins of their infection because those records had been lost or destroyed. Many people in this situation had, because of this, also been unable to get any assistance from the current support schemes. Sir Robert acknowledged that this was one of the important areas he would need to consider carefully when considering his recommendations.

10. There was also an issue with what records that did exist not always being accurate and reliable - often because of assumptions made by medical practitioners and their support staff who were unaware of the contaminated blood issue (for example, assuming that infection was a result of sexual promiscuity or drug use, and recording such in records). Many records were also inconsistent and open to interpretation. This meant that they often therefore did not meet the current schemes' proof requirements for proving the balance of probabilities.

What Form Should Payment of Compensation Take?

11. As mentioned above, some form of hybrid system was thought most likely to work as a system to pay compensation, with potentially some form of upfront lump sum payment, followed by an additional individual needs assessment process for those seeking additional recompense.

12. There was general support for the current support schemes to continue in some form. However, there was a general feeling that the community was concerned about the divergences in the different national schemes and general parity issues, which most would

not want to see continuing in future and that there would be general support for consistency amongst the schemes. Even if the schemes remained, they would probably need some reform to make them less rigid and more customer focussed so that they were better meeting the needs of beneficiaries. They would also need to be presented (for example by changing their names) in a way that would reduce the stigma associated with payments so as to help the healing process.

13. Similar to earlier meetings, attendees agreed that it was important for any compensation system to include a range of non-financial elements, particularly dedicated ongoing medical and psychological support, along with some commitment to priority access to healthcare. There needed to be a coordinated approach to this care, as up until now there had been a distinct lack of coordination and crossover between any care offered for victims' various problems. This has become an increasingly important issue over the years, and would likely be the most important part of compensation for many. One way to achieve this might be to set up specialist clinics for the blood infection community. There was some experience in offering such services (particularly on psychological and trauma support) in the private sector - though it was not cheap - but there was currently a lack of the relevant skills and knowledge within the NHS. Embedding psychological support within the existing haemophilia centres would also probably be a good start.

14. A further area of non-financial support would be the Government setting up a scheme, or working with the insurance companies to ensure it happens, that addressed the problem that the infected have in obtaining insurance. Merely enhancing payments to cover increased premiums would not be the complete solution, as many were simply refused insurance cover entirely.

Other Issues

15. Some concern was expressed that there did not currently seem to be any national policy about follow-up support for those that had cleared infections, and little in the way of research or studies on this issue. This made it hard post-infection to persuade medical practitioners to offer follow-up scans and tests.

16. One of the difficulties in looking at how compensation might be applied to the HIV infected, was getting a handle on accurate numbers on how many infected might be beneficiaries. Of the approximately 1,250 victims thought to have been infected with HIV through blood products, it was estimated that around 250 were still alive - but that figure could be as low as 200 - it was difficult to pin down precise numbers. More recent figures had been obtained from the Government via Freedom of Information requests, but there was some concern that these reflected numbers of beneficiaries registered with the existing support schemes, which might not give an entirely comprehensive picture of who might be eligible for compensation.

17. An attendee had some experience of the class action, around 2004, that was brought against the pharmaceutical companies in the US that had supplied infected blood (the issue of compensation payments / punitive damages by the pharmaceutical companies has been raised a number of times throughout the consultation process). The action represented

infected people from around the world, including from the UK. However, the outcome of that litigation exercise showed how difficult it would be in pursuing recompense from the pharmaceutical industry - the Judge had ruled that for those outside the US, there was insufficient evidence to suggest that the pharmaceutical companies had been responsible for their infection and dismissed the case. A certain amount of money had been offered as a consolation payment for closure to the action - amounting to around \$32,000 per claimant (of which legal fees took \$7,500) - but that had been accompanied with the signing of a waiver not to sue the pharmaceutical companies in any other country.