

DISCUSSION FORUM NOTE

Infected Blood Compensation Study (IBCS): Discussion Forum on Issues Affecting the Affected - Monday 22 November, 2021

Time: 11.00 am - 2.30 pm

Attendance via Google Meet: Sir Robert Francis QC (IBCS); Amy Street (IBCS); David Kirkham (IBCS); 23 members of the infected and affected community that had expressed an interest in issues affecting those adversely affected by the blood infection tragedy.

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 thought that it was important to spread the net wide to cover all the categories of infected and affected that were mentioned in the Terms of Reference - but also to others who were primary carers or could prove they were significantly affected in some way. In particular, it was important that siblings not be left out of the compensation process, as they were less talked about than other categories. A wide scope was required to address some of the weaknesses in the current support schemes where many of these deserving people were overlooked.

6. There was also strong support for the infected and affected not to have to justify their case to entitlement again and again - existing evidence provided either to the current support schemes or to the Inquiry should be used as an underlying baseline for entitlement for compensation.

What Should Compensation Cover?

7. Discussions on what compensation should cover crossed a number of recurring themes, some of which were general in nature and had been raised in other forums and the public consultation process, and some of which were particular to the affected community. These themes included:

- **Lack of Consent** - there should be an element of compensation that recognises that victims of infected blood had not been properly informed of the risks at the time(s) of their initial infection (where the risk of contaminated blood had generally been known for some time), which in turn had produced an inability for those involved to make properly informed decisions about their own wellbeing and resulted in a general lack of informed consent. This lay at the core of much of the pain and anger felt by many infected and affected;
- **Trauma** - the impact of watching a loved one's pain and suffering from having to live day-to-day with debilitating and deadly illness was immensely traumatising for those close to the infected;
- **Guilt** - any compensation paid to the affected needed to take account of the severe guilt felt by many affected. This could take many forms. For parents, it tended to centre around the decisions they made on behalf of their (often very young) children which were directly related to the circumstances of their child's initial infection. For siblings and children, it often came in a form of survivors' guilt, particularly in families with multiple infected individuals where the nature and severity of infection often took different trajectories. This could be particularly acute within haemophiliac families where these issues built up generationally, and where there can be guilt associated with being a carrier, whether linked to subsequent infection or not;

- **Medical Malpractice** - some form of recognition of collective medical negligence and wrongdoing, and subsequent cover up, which has allowed this tragedy to drag on unresolved for decades;
- **Loss of Earnings** - the tragedy had caused long-term disruption or curtailment of both individual careers and the ability of entire households to provide financially stable environments - compensation needed to take account of loss of earnings and pensions for all those adversely affected, the infected along with their primary carers (which might include adult children as well as partners);
- **Passage of Time** - compensation needed to take account of the significant length of time it had taken to bring the infected blood tragedy to some form of satisfactory resolution and recognise the adverse impact on the infected and their families and carers over this extended period.

What Form Should the Assessment Process Take?

8. There was a general feeling amongst attendees that there should be some underlying general principles built into the compensation process that allowed for a collective solution to be applied to everyone and which would allow a general baseline settlement to be produced that could be paid across the piece to everyone affected. This should not require any significant or onerous assessment process, particularly for those already registered with an existing support scheme who had, by definition, already successfully gone through the process of proving entitlement. On top of this, the system could then allow some degree of individualised assessment that looked at specific hardship cases and unique circumstances, for those that wished to pursue additional redress above the baseline settlement. This fitted with the general hybrid model for a compensation framework that had been raised in previous discussion forums.

What Form Should Payment of Compensation Take?

9. As set out above, many attendees were keen that there was an initial collective baseline lump sum settlement across all those eligible that would be easy to administer and could be paid quickly (and which might also include some form of partial interim payment prior to the completion of Sir Brian's Inquiry, which would be welcomed by many - even if modest in nature - as providing some urgently needed financial security and stability). Once a general settlement had been paid, those who wanted their individual cases looked at - either because they considered their particular circumstances extraordinary and/or because they were seeking public recognition and acknowledgement of their travails as an essential part of obtaining personal closure - could pursue individual assessments with a view to seeking additional recompense. Individuals then should have the choice as to whether to receive such payments as single lump sums or as annualised payments.

10. Many attendees were keen for the existing support schemes to continue in some form, though there was less consensus as to whether compensation payments needed to be delivered through the current devolved nation processes or could be delivered by a UK-wide

scheme. Some felt, however, that the current devolved mechanisms offered the advantage that existing relationships were already in place and that it was easier to communicate with localised devolved schemes than with a centralised one. Whatever delivery mechanism was chosen, there was a strong desire amongst some that a parity should be maintained across the UK and that there should not be a return to divergent payment systems. As in other discussion forums, attendees considered it important that there was a firm and unambiguous commitment (given legal/legislative force if necessary) that the schemes would continue for the lifetime of the infected and affected.

11. There was currently (and historically) an issue with the severely limited provision of consistent and timely physical and psychological support, both for the infected and the affected. This was down to a systemic failure in the medical care available in the UK - there should have been systems that kicked in to alleviate many of the issues faced by the infected over the decades since this tragedy began, but there was little evidence of this having happened. There was a need to remedy the failures of the past and to protect against such situations arising again in the future, including there being an open and public discussion on how to make sure it never happens again. It was therefore important that a compensation package included some form of ongoing medical (including palliative and end of life care) and psychological support services which understood the specific circumstances and needs of the infected and affected community. There should also be some shared learning from provision of these services, with treatment of one patient filtering into the treatment of others in a holistic way. As in other meetings, it was suggested that such services could be accompanied/supported by some form of healthcare passporting system, which allowed patients priority treatment because of their infection(s).

12. There was a feeling amongst some that compensation also needed to contain an element of exemplary and punitive damages which acknowledged some degree of fault - this was particularly prevalent amongst the haemophilic community, who felt that they had been particularly ill served by the medical profession, having been repeatedly tested upon and subject to a barrage of tragic events like those at Treloar College. General damages for what had happened did not seem to suffice. There was discontent amongst some that the pharmaceutical companies had not been held more to account for the decisions they had made - along with some resigned recognition that the few limited attempts to do so (such as via class actions) had mostly proved futile (at least for those outside the US).

Other Issues

13. There was a desire for a general acknowledgement of the urgent need for wider family support across the entire response to the infected blood tragedy - this needed to be built into all aspects of any response and support provided. Too many had experienced circumstances where they were told by medical practitioners that the physical medical needs of an individual infected could be treated, but that any support for the wider affected family was outside their remit to consider. Going forward there had to be some continuity of service in place for everyone, and an expectation that there should be access to the same level of services wherever you lived in the UK.

14. As had been raised at previous meetings, attendees considered that it would be helpful if there was some form of financial advice available to those who received large sums through compensation to assist them in effectively managing this money. This might be provided through a dedicated (though independent) advice service built into the payment scheme itself or could take the form of recommendations as to suitable accredited private providers.