DISCUSSION FORUM NOTE

Infected Blood Compensation Study (IBCS): Discussion Forum with RLRs on Legal and Legislative Issues - Tuesday 14 December, 2021

Time: 10.00 am - 1.00 pm

Attendance via Google Meet: Sir Robert Francis QC (IBCS); Amy Street (IBCS); David Kirkham (IBCS); Dr Sonia Macleod (University of Oxford); 17 representatives from the Recognised Legal Representative (RLRs) organisations (including Queen's Counsel).

Introductions

1. Sir Robert welcomed all the attendees to the forum and thanked their organisations for setting aside time to come and both represent the views of their infected and affected clients and to discuss with him a number of the technical and legal issues that will need to be addressed in order to establish a successful compensation framework for infected blood.

2. Sir Robert went on to explain that he had now successfully held a number of discussion forums attended by a range of members from the infected and affected community and their representative organisations. These meetings had allowed him to speak directly with over 100 infected and affected individuals and hear their stories and experiences. This was in addition to the many hundreds of written submissions the Study had received as part of its consultation with the infected and affected community. He felt that it was right that he had started this process with a blank sheet of paper and by listening to those directly affected by this tragedy.

3. As this period of consultation was now drawing to a close, Sir Robert needed to turn to look in detail at the issues that would help shape his recommendations for how a compensation framework for infected blood might work. He was very pleased to be able to hold this discussion with the RLRs in order to draw upon their extensive legal experience on these issues, which would add to the written submissions they had already made as part of the terms of reference consultation and were currently formulating for their final written submissions to him.

4. The RLR representatives introduced themselves, gave a flavour of their experience in relation to the infected blood tragedy and a short description of the nature of the clients they were representing.

Presentation

5. Sir Robert wanted to open the discussion with a look at how past compensation schemes across the UK and in other countries had been established to address both the

infected blood tragedy and other similar medical issues. He was very pleased to introduce Dr Sonia Macleod, Research Fellow at the Centre for Socio-Legal Studies at the University of Oxford, one of the authors of *"Redress Schemes for Personal Injuries"*, which had looked at a wide range (over forty) of international non-litigation personal injury compensation schemes. Sir Robert had asked Dr Macleod to share some of her experience with the forum and make a short presentation to set some of the context for the discussion.

6. Dr Macleod's presentation (the slides of which have been circulated to attendees) took the forum through a quick history of some of the most relevant schemes which her research had identified, explained the nature of those schemes in terms of coverage and outcomes, dipped into the detail of how some of those schemes were structured and operated, and their statutory vs. non-statutory status, and outlined the key pros and cons that could be identified from the success (or otherwise) of the schemes. She then set out a number of issues that the meeting might want to consider, including: accessibility for claimants; clear eligibility criteria; the specific nature and quantum of redress; and how a scheme might be administered.

Issues Discussed

7. Sir Robert explained that a number of key questions had emerged from the significant representation he had received. The first was around the general form of the scheme, on which respondents held a wide divergence of views, that principally came down to the tension between two different approaches - a simple tariff-based system or an individualised tribunal-like system. The second was to what degree a compensation scheme needed to cover issues which would not normally attract tort compensation (e.g. provision of psychological support, the effect on secondary victims, etc.). And the third was how any scheme interacted with and took account of current social support (such as the existing devolved support schemes).

Punitive Damages

8. There was discussion on the important issue of whether compensation should include a punitive element. Should it include the equivalent of aggravated and exemplary damages? There had been discussion within the infected and affected community about the importance of an apology. There was a link between an apology and the consideration of aggravated and exemplary damages, as not all harm could be recognised and quantified in terms of loss - taken alongside consideration of aggravated and exemplary damages, a sincere apology could go some way to acknowledging the types of damage that was hard to quantify by traditional means. There were a range of issues that punitive damages might need to address: the administration of products without adequate warnings or consent; non-consensual research; covering up information; lack of provision of information; how people have been generally treated. The question was whether to try to treat these as individual elements (which might require a significantly complex process and individual assessments) or whether to look at them as a single piece across the board and have a fixed amount or uplift (possibly for different categories of victim).

9. There was a feeling that exemplary damages could probably work as a fixed sum across the piece, but that this would need to work differently for aggravated damages, for which there was more of a need for an individual assessment of the severity of harm (which may require a tiered hierarchy of aggravated damages). There was, however, no reason why these two approaches could not work side by side.

10. There would need to be some thought on what function punitive damages served. In many cases, it was usually to prevent recurrence - that would not really fit with the infected blood tragedy, where processes had changed over time to make this unlikely. In this instance, therefore, there may be a need to look at another way of framing it. Is the primary rationale to punish and prevent or is it to acknowledge and recognise the harm that has been done? Under the Republic of Ireland compensation scheme, it was framed as the redress of avoidable harm. However, there was a risk in presuming that the recurrence ship had sailed, as there was still some concern within the Haemophilia community that other similar issues may still be on the horizon (e.g. issues and consent around gene therapy).

Missing Records

11. There was some discussion around how a compensation scheme would look at the issue of missing, destroyed or edited medical records, in particular in relation to proving the source of an individual's infection. This had become a particularly important issue with the infected blood tragedy, and Dr Macleod was asked whether this was a unique issue or whether other schemes had faced this challenge. Dr Macleod explained that the issue had occurred in other instances - it had been raised as part of the Cumberlege Review - but that in many instances it did not arise as some schemes did not require the production of that level of proof. For example, the vCJD scheme only sought proof of diagnosis and residence - which took the issue of how infection occurred out of the equation. Schemes that looked at how infection was acquired often faced problems, in particular around trying to attribute between lifestyle choices and treatment.

12. Any scheme needed to have mechanisms to work around that issue. Any eligibility process needed to be both flexible and reasonable, and there probably needed to be a careful examination of whether evidence was really needed (or, at the very least, equal consideration given to other forms of evidence). Eligibility needed to be supported by a scheme, not obstructed by it. Sir Robert added that it was likely that any solution to this issue would be informed by the findings of Sir Brian's Inquiry, which might suggest a route to evidence (where deemed required).

Current Compensation Law

13. This issue was raised as to what degree a compensation scheme needed or should be bound by the constraints on current common law. In particular, in relation to the need for individual claimants to be able to prove that there was some degree of negligence, and the degree to which the emphasis to provide supporting evidence primarily remained with individual claimants. To what degree might engagement with the existing support schemes be taken into account or act as a proxy for having already proven eligibility (and therefore equate to an automatic entitlement)? Many clients were of the view that having to prove their case yet again would be a trigger for additional trauma.

14. There was general consensus that any compensation scheme should not be limited by current common law concepts of damages. However, there was an issue (which was probably more or a moral than a legal one), if compensation went beyond what might be available through traditional court compensation, would that be perceived as the State accepting responsibility in the place of aggravated and exemplary damages, and would that be an acceptable approach?

Access and Support

15. Whatever the mechanisms for delivering compensation were, including potentially delivering it through the current support schemes, there needed to be careful thought given to how individuals engaged with the application process. There would be a need to have a single portal or front end to the claim process that was easy to understand and accessible by everyone - rather than leaving individuals to navigate through a disparate series of differing routes. This was important to both removing a potential stress in navigating through the eligibility process and on projecting a sense of equanimity, even if the actual payment mechanisms were to remain as they currently are.

16. There also needed to be some provision of advocacy support for claimants. This did not necessarily need to be legal representation for typical cases - it could merely be a friendly voice speaking on behalf of claimants where needed. But would probably need to be a lawyer advocate for the more complex arguments and cases, including additional legal professional support where necessary.

Loss of Opportunity

17. There needed to be some thought on how the economic loss of victims was reflected within a compensation scheme. Claimants are likely to have significantly different views on what they might have achieved in life had they not been infected, and are likely to want some form of financial redress to that loss reflected in any compensation settlement. However, a simple tariff system may be difficult to apply on this issue, because of the very bespoke nature of individual claimant's circumstances - so this is likely to require some form of individual assessment process. While this would be of clear benefit to individual claimants, it would be a very time consuming process as it would involve a range of evidence and require the employment of experts.

18. Reported experience suggested that the Windrush Scheme had proved challenging to implement this issue in a practical way, e.g. in proving what people would have done with their lives and the jobs they might have had. Any scheme therefore needed some protective measures built into its administrative processes, so that harsh, arbitrary and unjust decisions were not routinely made which added more insult to existing injury.

19. Sir Robert explained that there was evidence to suggest that a tariff approach could work in such circumstances, but that the tariffs needed to be set at the right level. He noted, by way of example, the US 9/11 compensation scheme. A lot of the victims had been high earners. A tariff was set as the presumed mode of redress, using a percentage of median income - though the level chosen had been deliberately generous (above average) so that it

was felt it would capture most of those claiming. However, there was then an option for claimants to seek a more detailed assessment if they did not consider this sufficient.

Potential Interim Payments

20. Many clients were looking for a quick closure and peace from the whole process, as they just wanted to get on with their lives. As such, some level of generous and early (or interim) settlement would likely be welcomed and accepted by many. However, it was acknowledged that it might be easier to look at some form of entitlement to an interim payment if only considering those claimants already known about (e.g. infected on existing schemes), but might be considerably more difficult and complicated to extend its reach (e.g. to those affected not currently covered). It might be difficult amongst the RLRs' clients to reach any consensus on that issue.

Acknowledgement of Harm

21. Whether as part of the compensation scheme, or Sir Brian's findings, or both, there needed to be some form of acknowledgement of the harm that had been suffered by the infected and affected. This did not necessarily need to be accompanied by an admission of culpability, though many were pushing for that as well. It needed, however, to cover not just the direct harm of being infected by the State, but also the wider, indirect harms suffered, such as the effects of a lack of information or misinformation both from and amongst the medical profession (e.g. infected being repeatedly told that their Hepatitis C infection was more likely caused by being serious drinkers).

22. Ideally, this would go hand-in-hand with both some form of apology and an explanation of measures that were being put in place to ensure such circumstances did not happen again. The drafting around the key principles for a scheme would be important to setting a strong message.

Anonymity

23. Many clients were keen for any compensation scheme to be designed with maintaining the anonymity of claimants in mind. Some people had felt unable to put themselves forward - either to make claims of the current support schemes or to participate in Sir Brian's Inquiry - without some form of guarantee of continued anonymity. It could not be an afterthought - it needed to be carefully and sensitively designed into the system (e.g. absolute IT security; strong data protection policies; etc). Any scheme is not just about providing financial redress, it is also about supporting the care of beneficiaries and enabling closure moving forward. Anonymity was a key component of this.

Future Proofing

24. Any scheme needed to have some core principles built into it from the beginning (such as treating claimants with dignity), which were centred around allowing people to get on with their lives. It needed to be built on a holistic approach to meet all of the potential needs of beneficiaries. As such, its systems needed to be flexible and responsive to changing circumstances, and needed mechanisms to allow it to look at and address new

issues and future difficulties that might arise. This would require a two-way dialogue that was currently difficult with the current support schemes. Ideally, this would also require the scheme itself to act in the role as advocate for its beneficiaries.

25. Dr Macleod pointed out that one of the benefits of schemes that went down the route of periodic payments, was that they had the ability to adjust to known risks as they moved forward, as opposed to single lump sum (including litigation-based) schemes where they were trying to predict the unknown. Such schemes tended to deliver better outcomes over the long term.

Non-Financial Support

26. It was important that any compensation settlement also included elements of ongoing support that were non-pecuniary in nature, which included healthcare, psychological support and palliative care. Many were looking for some form of priority health passporting system, similar to that established in the Republic of Ireland. It was recognised, however, that such a system might be difficult to sell to the government and NHS, as they would then come under intense pressure from other groups for similar preferential treatment. An alternative, therefore, might be bespoke care packages that were built into any compensation scheme, which would achieve similar outcomes (an example being the National Care Package funded by the Department of Health available via the vCJD Trust to those who become eligible to the scheme). Another approach might be to establish specialist centres, which could look holistically at the needs of patients and which were co-located with other advice and support services. However, while such centres cut down on the need for patients to travel around, there were geographical and logistical issues in establishing them, as well as issues of patient trust and credibility.

27. Identifying gaps in support services (such as the current lack of expert psychological and trauma support), and enabling the training and expertise to fill these gaps, were also key to improving the support to beneficiaries. Merely providing financial redress was insufficient if there were not appropriate services available, even in the private sector, for beneficiaries to engage with. The geographical discrepancies between those services that are available has also been a historical issue. Many clients were also concerned that much skill and knowledge was being lost as time wore on, as they were often having to repeat and explain circumstances anew to a new generation of younger medical professionals.

28. Being able to incorporate non-financial forms of support was one of the advantages of compensation schemes over a purely litigation approach, as they were not bound by the constraints of common law and could offer their support to a much wider cohort of claimants.

Independent Oversight

29. Given the above, it was felt that there might need to be some independent oversight of any scheme, or at the very least some input directly from the community. This could take the form of an Ombudsman-type role. Someone who could engage with the community and look to address some of the issues that beneficiaries had with the existing support schemes, as well bring together the disparate sections of the community in a commonality of goals - something which was currently difficult to find consensus on.