

INFECTED BLOOD INQUIRY

SUBMISSIONS ON FURTHER DISCLOSURE

ON BEHALF OF THE HAEMOPHILIA SOCIETY

1. These submissions are made by the Haemophilia Society (“the Society”) on its own behalf and on behalf of its members, to include those designated with Core Participant status in the Infected Blood Inquiry (“the Inquiry”) and represented by Eversheds Sutherland (International) LLP. This submission relates to the minutes of the Infected Blood Expert Group (“the Expert Group”) as disclosed on 21 May 2025 and other documents disclosed on 21 and 23 May 2025. This submission should be read in conjunction with the submissions made on 23 May 2025. The bundle of documents contains 41 sets of meeting minutes where the Expert Group met to discuss the various issues surrounding compensation.
2. **Establishment of compensation scheme**
 - 2.1 It is clear from the disclosed documents that there was significant consideration as to the establishment of the compensation scheme and which government department should be responsible for its administration. The Chair’s recommendation was clear that an arm’s length body should have been established to ensure independence from government, but this was immediately discounted seemingly as a result of a desire to be able to monitor the amount spent. Various papers were produced outlining the options, to include CABO0000913 and CABO0000914. CABO0000914 makes it clear that “*The Cabinet Office had no expertise in this area and had no capacity to administer such a scheme*”. The appropriateness of the Cabinet Office undertaking this role was considered as was the appropriateness of the Department of Health and Social Care, however, the latter was discounted on the basis that the infected and affected community would not have supported that. Either way, neither option would have fulfilled the anticipated independent body model as envisaged by the Chair in his clear recommendations.
3. **Engagement with the Community**
 - 3.1 The Expert Group first met on 1 February 2024. During that first meeting, the Cabinet Office confirmed that only the Chair’s name would be published at that time. No explanation is provided within the documents, or elsewhere, as to why this was the case and the other members of the group should be granted anonymity. In fact, the minutes of the meeting of 8 February 2024 state “*The clinical experts agreed in principle for their names to be released at the conclusion of the Group’s work to help build trust with the community*”. The Society therefore questions why it was decided that the members of the group should be granted anonymity until the conclusion of their work, when to do so has created further distrust within an already (understandably) distrustful community (as identified by the Cabinet Office in the above quote).
 - 3.2 At that very first meeting on 1 February 2024, the Expert Group acknowledged that it “*may be helpful to engage the Hepatitis C Trust and NHSE in stakeholder engagement for Hepatitis C*”. There was no obvious recognition that others within the community

may also have been able to inform the setup, had they been asked. There is also no evidence to confirm that the Hepatitis C Trust and NHSE were actually asked to contribute to these early discussions, or at all. Likewise there is reference to the All-Party Parliamentary Groups (“APPGs”), specifically the APPG on AIDS and HIV, but no reference to the APPG on Haemophilia and Infected Blood, where the majority of the discussions surrounding the Inquiry’s recommendations and future compensation have been discussed. Again, the Cabinet Office unilaterally decided who should be on the Expert Group and who should be engaged with as part of the setup process.

- 3.3 Throughout the disclosed minutes it appears that there was consideration to engage with the community and, in the main, these considerations were agreed by the Expert Group. Despite this, for reasons that remain unknown, there was limited or no community engagement flowing from these Expert Group meetings and proposals for meetings with the various advocacy groups and local Haemophilia Societies were not acted upon.

4. **Applicable compensation categories**

- 4.1 At each meeting it appears that discussions took place in respect of the severity levels of the infections, the impacts on the individuals and how the suffering and pain should be compensated for under the scheme. For example, during the meeting of 15 February 2024, a discussion took place in respect of stigma and the ways in which compensation should be quantified in those cases. It is also clear that a number of the actions (or inactions) complained about by the community were in fact discussed by the Expert Group, for example, on 15 March 2024, *“it was noted that long-term support was desired by many in the community”*. However, ultimately the long term support schemes were removed when the scheme was announced on 21 May 2024, only for them to be reinstated when Sir Robert Francis consulted on them.
- 4.2 In respect of the Special Category Mechanism (“SCM”), there is evidence that there were various discussions around transporting this to the new scheme. However, ultimately this has not been acted upon and the SCM removed. The Society refers to paragraph 7.14 of its general submission of 23 May 2025, where the process for being eligible for the SCM is discussed and the impact of removing this from the compensation scheme. Again, it is clear that the Expert Group understood that removing the SCM could cause difficulty for some, but the Society is uncertain as to where or how the decision to not transport the SCM to the new scheme was made.
- 4.3 To demonstrate the above, during the meeting of 10 July 2024, the SCM was considered in detail, the minutes state *“A preference for the current supplementary route was expressed, whilst addressing that new entrants to the scheme would likely be rare. It was clarified that individuals that were receiving SCM currently would passport to this framework rather than have to demonstrate eligibility, whilst new participants would be subject to specific eligibility criteria, aligned with the financial loss associated with cirrhosis”*. This approach continued into the 31 October 2024 meeting where it was stated *“The Expert Group agreed that those with Hepatitis applying for the health impact supplementary route due to SCM should have a tariff adjustment close to those who had cirrhosis”*.

5. **Conclusion**

- 5.1 It is clear from the disclosed minutes that the Expert Group was alive to the various concerns in respect of removing certain categories of support payments where individuals had previously successfully demonstrated eligibility. However, the decisions were made to proceed regardless.
- 5.2 The impact of the Expert Group meeting in private with an unknown membership on the infected and affected cannot be understated. The community has campaigned tirelessly for decades and has previously been trusted to engage with schemes in order to ensure that they are fit for purpose. Unfortunately, lessons from the past have not been learned and this now feels like a further betrayal of trust which has resulted in a system being created that is not fit for purpose. In addition, it is clear that the Chair's recommendations have been drastically diluted to the detriment of those who should be eligible for compensation.

28 May 2025

Eversheds Sutherland (International) LLP