

Sir Robert Francis QC
Infected Blood Compensation Study
Room 408 Cabinet Office
70 Whitehall
London
SW1A 2AS

9 August 2021

Dear Sir Robert,

Response to Consultation on Terms of Reference

The Haemophilia Society welcomes the opportunity to feed into the draft Terms of Reference for the Infected Blood Compensation Framework Study (the Study). We believe it is vital that this work is completed prior to the conclusion of the Infected Blood Inquiry and the results of The Study be submitted to the Infected Blood Inquiry. This community has waited decades for compensation for the harm done to them. We hope the outcome of this study will expedite any financial payments as well as consider non-financial compensation to those infected and affected.

When looking at the framework we think that the Study should consider a wide range of aspects, not just the immediate impact of being infected. This should include:

- The long-term impact of treatment for viruses contracted through contaminated blood
- The long-term impact of treatment for those viruses, when combined with pre-existing conditions such as haemophilia and Von Willebrands Disease
- Side effects of treatment
- Psychological and social impacts of those infected and affected.
- Future needs due to reduced capacity and long-term health conditions.
- Financial consequences of infection such as reduced ability or complete inability to work, and obtain financial services

Some underlying principles about how the Study is conducted must be considered.

This community often feels their opinions have not been heard and consequently a lack of consideration and scrutiny is given to its unique needs. We would encourage Sir Robert to ensure there are ample opportunities and easily accessible methods for people to provide input to this Study. There needs to be effective communication to guarantee that the views of all those infected and affected are gathered with no one left behind.

For everyone affected by a genetic bleeding disorder

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Decisions have been made, and continue to be made, without the knowledge of those affected and infected. We would expect the study to operate with transparency regarding its methodology and processes to instil confidence in this Study.

Below are comments based on the original draft terms of reference points:

To consider the rationale for such compensation

We agree that the Study should look at the rationale for compensation. However, we would not expect this Study to recreate the work of The Infected Blood Inquiry, but rather look at the extensive evidence from people infected and affected and the impact this has had on them and their families. We would expect the Study to consider the moral and ethical responsibility of the harm done to this community and the response of those giving evidence and responding for those who should act to protect its citizens.

The Prime Minister, when she first announced the establishment of an Inquiry, back in 2017, spoke of "an appalling tragedy which should never have happened". Your sponsoring minister, Mr Lidington, later stated: "The infected blood scandal of the 1970s and 1980s is a tragedy that should never have happened."

Those are words from government ministers. However sincere they are, they cannot convey or comprehend the full knowledge and experience of those directly affected by the events that you are charged with investigating. But, on behalf of my clients, I do say that those words, the acceptance that this should not have happened, is an acceptance that things went wrong. Things happened that should not have happened and so, on behalf of my clients, I say, unreservedly, that we are sorry. We are sorry that this should be so, that this happened when it should not have done.

This is the beginning of a journey to uncover exactly what happened and why, but from those I represent it begins with an expression of sorrow and regret
[26 September 2018, transcript page 15, line 6 to page 16, line 1]

- That the Study look beyond the limitations of conventional legal principles on compensation to the affected and infected as part of this framework.

"A government which takes upon itself the role of public provider of medical advice and clinical services is in a very different position to any commercial organisation. It is clearly arguable that their duty to innocent citizens who suffer injury under the aegis of such treatment has a moral dimension to it which should distinguish their assessment of their position from that criteria to be adopted by other defendants of a corporate character.

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Government owes a duty under this to its shareholders or insurers. It should also mean that the public may be entitled to expect from government an appraisal of their position which is not confined solely to legal principles to be found in the law of negligence, or problems of proof.

... The plight of the plaintiffs - or many of them - is a special one:

[Extracted from the open letter by Mr Justice Ognall titled “Haemophilia/HIV Litigation”, dated 26 June 1990 (DHSC0046964_024). This document was referred to during the oral evidence of Lord Kenneth Clarke to the Infected Blood Inquiry on 28 July 2021. See transcript page 205, line 22 to page 206, line 15.]

- Compensation for nonphysical harms such as testing and treatment without consent, misuse of data, and psychological and social impact must be considered within the “rationale”.
- Consideration of the impact of treatments and side effects and long-term implications of these treatments and impact of ongoing care and complications should also be looked at within the rationale.
- Consideration of the potential future impact of infection with viruses, such as vCJD, where the full consequences may as yet be unknown.
- Compensation should look at non-financial aspects such as access to health and benefit passporting, provision of equal insurance and access to financial products.

Give independent advice to the government regarding the design of a workable and fair framework for compensation for individuals infected and affected

We agree that the Study should look at the design of a fair and workable framework. We would emphasise the need for a robust consultation process to ensure the views of a varied and wide-ranging community are collated to ensure all opinions and needs are gathered.

- We would suggest under this section that workable would include a degree of flexibility built in so that all needs can be adequately met.
- There should be transparency about the way the framework has been developed with clear evidence of thinking based on consultation responses and consideration of the needs of all infected and affected.

To consider the scope of such compensation, and whether it should be extended beyond infected individuals and their partners

We agree that the Study should consider the scope of the compensation framework.

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- We would expect the Study to examine the extent of who has been impacted by the infected blood scandal and who should be eligible for compensation. We would expect this to go beyond those infected persons and their partners and to include, but not limited to, affected parents, children and siblings, extended families and long-term carers.

To consider the measures for compensation, looking at other national schemes

We agree that the Study should look at other national schemes.

- We would suggest the Study look at the Irish Compensation scheme as a financial model and other global schemes which may offer suitable non-financial solutions which may be adapted for use in the UK. For example, aspects such as health passporting, access to care and treatment, including long term psychological support, equal access to financial products and security.

To consider the relationship between a compensation framework and the current financial support schemes

We believe the relationship should be considered as part of this consultation.

- Long term support should continue but with a guaranteed security of continued payment for life which currently they are not. The consultation should consider the best mechanism to provide security of income for infected and affected.
- No one should lose out financially or in any other aspects under any proposed changes to schemes.
- If considering support schemes in line with compensation, then this needs to be looked at with parity and complexity of devolved nations in mind.
- Consistency of approach between the devolved nations needs to be ensured long-term, to avoid the divisive experiences of recent years where beneficiaries have received different support payments depending on where in the UK they were infected.

To consider options for administering the scheme.

Historically, this community has had to interact with a multitude of trusts and schemes. Many of the community have suffered additional harm and humiliation as a consequence of the schemes administration. Great care must be taken to ensure this does not happen again compounding the pre-existing harm. We would expect the Study to look to failures in the past to ensure these are not repeated.

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- Any administration system must work for the whole community and be adequately resourced to be efficient and empowered to act with compassion and understanding to ensure that no further harm is done to the community.
- We would advise a degree of flexibility to be built into any scheme to better service all needs.
- Consideration should include how to include active user input and ongoing consultation to the administration to ensure the scheme is fit for purpose and deliverers for those it has been set up to serve.
- Consideration should be given to ensuring parity across the devolved nations.
- The level of burden of proof for individuals applying to the scheme should be looked at especially in the light of the period of time that has passed and the acknowledgement that destruction of medical and other records has taken place.

Submit to the Government its report and recommendations as quickly as possible and no later than the end of February 2022, to provide the Government with advice on potential options for compensation framework design.

We agree there is a need to ensure that a framework is in place to provide for the needs of the community is in place but with assurance that the views of all of the community have been extensively consulted upon and recommendations can be made with confidence that they can that serve all of those infected and affected.

Other Considerations

There needs to be clarity over the situation with regard to devolved nations and the adoption of recommended frameworks and the administration of any schemes in the devolved nations. There has been a history of disparity across the UK, and this is something we strongly feel must not happen again to our community.

Yours sincerely,

Clive Smith
Chairman of board

Kate Burt
CEO

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