

## The HIV and sexual health charity for life

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



23 July 2021

Dear Sir Robert,

I am writing to you about the consultation on the terms of reference for the independent study looking at options for a framework for compensation for the victims of the infected blood tragedy. Thank you for the opportunity to feed into this.

As you may know, when the Macfarlane Trust was wound up in 2018, Terrence Higgins Trust was gifted its remaining assets to continue providing support and advocacy for its service users. As a result, we have been working closely with former Macfarlane Trust registrants to understand and address the issues and challenges they face as a result of HIV infection via contaminated blood products prescribed by the NHS.

There are five main areas for consideration that I would like to raise with you regarding the terms of reference and how the study moves forward.

Firstly, I would urge you to give significant weight to how important this study is for those infected and affected by HIV as a result of contaminated blood. What happened continues to have a profound impact on the lives of this group of people. This impact is not just as a result of what I regard as the medical negligence that led to people being infected but additionally as a result of how they have been treated by those in authority. I welcome the decision of the Cabinet Office to offer some limited funding for legal representation for the consultation on the terms of reference for this study. But to give those who will be most impacted by the outcome of your study confidence that this is a fair process where their voices are truly being heard, I would urge you to use your influence to secure legal aid access to support their representation to your study in its entirety.

Secondly, I find it concerning that there is consideration being given to not including all those covered by the ex-gratia scheme, the Macfarlane Trust. I have attached the relevant section of the deed we signed in 2018 that defines the beneficiaries. What was written in our deed is a reflection of the parameters established at the inception of the Macfarlane Trust. That this was overlooked when the infected blood support schemes were created was a disgrace. At the Infected Blood Inquiry, we have seen several senior civil servants claiming that they were unaware of the Macfarlane Trust deed with reference to groups of people being excluded from support. It would be very disappointing to see this omission being repeated in your study.

**Patrons include:**

Lord Black of Brentwood  
Simon Callow CBE  
Lord Cashman CBE  
Julian Clary  
Martin Clunes  
Dame Judi Dench  
Tracey Emin CBE  
Lord Fowler  
Sonia Friedman OBE  
Stephen Fry  
Paul Gambaccini  
Lord Glendonbrook CBE  
Charles Hart  
Sir Elton John  
Lord Kirkwood of Kirkhope  
Beverley Knight MBE  
Canon Doctor Paul Oestreicher  
Professor Anthony Pinching  
Danny Rampling  
Gaby Roslin  
Sir Antony Sher KBE  
Dr Miriam Stoppard OBE  
Gareth Thomas CBE  
Dr Rupert Whitaker  
Tony Whitehead MBE  
Johnny Wynne-Williams

Thirdly, compensating those who contracted HIV as a result of contaminated blood is not just about financial reparations. This group of people so damaged by our national health service deserve the best healthcare it can offer with regards to HIV, hepatitis, vCJD and haemophilia as well as the comorbidities associated with these conditions. Today members of the Macfarlane community will get access to different healthcare options based on where they live and what services are available locally. They need a 'gold standard' of provision guaranteed and I hope it will be included in the scope of this study to recommend that.

Fourthly, I would urge you to consider as part of the terms of reference whether government can take action to improve the situation for many of the former Macfarlane Trust registrants around access to financial services. Many of those infected with HIV as a result of contaminated blood products have either been unable to access financial products such as insurance, pensions, loans and mortgages or have only been offered these products at exorbitant rates.

Finally, by definition, the community members infected with HIV lived with it either untreated for many years or they received treatment that was detrimental to their health. In addition to issues associated with being the first generation to live for decades with haemophilia, their HIV status has caused complications and comorbidities. This must be acknowledged. HIV then was very different from HIV now, a treatable condition today. With there being so many fewer people who have been infected and affected with HIV and hepatitis compared to those mono-infected with hepatitis, the former believe their voices have often been lost. For the partners who were infected with HIV, there is a very real sense they have been ignored. It would, therefore, be paramount to see a space for this community to be heard as part of the terms of reference, including an understanding of their distinct needs.

I look forward to submitting information to you for the study on behalf of the Macfarlane community. If there is anything specific we can assist you on with regards to this important piece of work please do reach out.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Ian Green', with a long horizontal line extending to the right.

Ian Green  
Chief Executive Officer