



Aldwych House  
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London  
WC2 4HN

The Rt Hon Nick Thomas-Symonds MP  
Paymaster General and Minister for the Cabinet Office  
70 Whitehall  
London SW1A 2AS

9 December 2024

Dear Minister,

I understand that this week you and your officials will have a series of meetings with representatives and members of the infected blood community.

In view of the concerns expressed to me and drawing on the experience gained during the Inquiry, I write this to emphasise how important it is that engagement should both be meaningful and informed by the findings of the Inquiry.

The background to this letter is something I feel sure you will have been made aware of by your officials: that, since the welcome announcements that significant compensation was to be paid through the Infected Blood Compensation Authority, there has been a groundswell of discontent with the way in which compensation, so long overdue, has been and is being managed.

It is of concern to me that what was initially unease and some confusion has been allowed to develop to an extent that should make any objective observer deeply uncomfortable. Thus, I have received a joint letter from the chairs of The Haemophilia Society, Tainted Blood, Haemophilia Scotland, Haemophilia Northern Ireland and The Hepatitis C Trust and a director of BTMK Solicitors asking me to do what I can to hold the government to account and to address some of the serious issues raised by them. I have also received a letter from Haemophilia Wales and a

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further letter from Tainted Blood. The letters can be found on the Inquiry website [here](#).

Moreover, these letters do not stand alone. I should let you know that, especially in the last two weeks, I have also separately received a large number of letters from individuals across the UK. The letters are differently expressed, from very different people, but all to the same broad effect.

The toll on campaign groups of supporting their members over the past few months, when they have more and more been expressing their frustrations, without access to legal advice or public funding should not be underestimated. One of the steering committees described itself as utterly overwhelmed.

I would draw your attention in particular to three central matters. The first is one of principle, set out at page 218 of the first volume of the [Inquiry Report](#) as one of the lessons to be learned. It is as follows:

***“Involvement in a decision of those affected by it***

- ***People affected by decisions need to be involved in them.***
  - *This is true not only in respect of their own medical treatment. It is necessary for any support schemes to involve the people affected by them. (See the chapters on the Macfarlane Trust, Eileen Trust, Caxton Foundation, Skipton Fund and National Support Schemes).*
  - *There is a fear, now, that the design of the compensation scheme to meet the recommendations made in the second report of the Inquiry may not involve those people whom it most centrally affects.*
- ***Paternalism is misplaced. This is true not simply of clinical practice (see the report of the ethical experts to the Inquiry) but also true of those administering support and true of politicians.”***

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I understand the involvement of people infected and affected to have been:

- consultation about the proposed scheme by Sir Robert Francis. This was announced by the previous Government, and following the consultation you met a limited number of campaign groups and accepted his recommendations in full apart from five.
- engagement by the Infected Blood Compensation Authority about their implementation of the compensation scheme.
- consultation by the Cabinet Office with campaign groups about the research award.

Your engagement with campaign groups this week would appear to be the first time that campaign groups have had an opportunity to engage directly with the Government since the publication of the scheme summary in August, despite repeated requests for meetings with the Cabinet Office.

From the Inquiry Report you will understand that people infected and affected have been through the experience of support designed behind closed doors and lobbying for reform when the inadequacies of this approach became overwhelming. This is why campaign groups want to help get compensation right in the first place. One communication to me has memorably described the approach to compensation as feeling like “*Macfarlane on steroids*”. The significance of this description is obvious to anyone who reads the Inquiry Report where it examines the establishment and conduct of the Macfarlane Trust.

I share the concern you expressed publicly about people receiving conflicting assessments about their access to interim payments to estates to recognise deaths as yet unrecognised. Might this perhaps have been avoided with better engagement?

The second central theme in the correspondence I have received is that of the practical independence of IBCA. In the [Inquiry's second interim report](#) in April 2022 I noted that:

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*“It must be acknowledged that legal independence from Government may not on its own be sufficient to dispel mistrust. The Macfarlane and Eileen Trusts were set up as charitable bodies independent of Government: yet the experience of those infected and affected of the ways in which they operated was not a happy one. The Skipton Fund was specifically established as an agent of Government (so there was no independence there except when it came to the appeal structures). Experience there, too, was unhappy.”*

I identified **five features of independent and trustworthy operation** of a compensation scheme as follows:

*“(1) there must be a sufficient guarantee of independence;*

*(2) the processes of the scheme need to be as transparent as legally possible;*

*(3) those set to benefit from the scheme (people infected and affected) must have a central influence on its decision-making and operation;*

*(4) there needs to be a clear, set, basis for establishing the scope within which any discretion held by the body can be exercised; and*

*(5) its decisions should be underpinned by a proper system of appeal, which should be a body which can take a fresh decision for itself.”*

It is a matter of considerable concern to people infected and affected that the real decision-making appears to be being undertaken by officials within the Cabinet Office rather than by IBCA as a separate and independent body and that what is happening in practice does not fully reflect the features described above.

This leads to me emphasising the third central matter underpinning the correspondence I have had, which concerns a further issue of principle: **the need for openness and transparency** – something which this Government will surely support given its commitment to legislating for a duty of candour.

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Just as I pointed out in the Report that an apology needed to be accompanied by action if it was to be truly meaningful, the principles of involvement and openness should never just be a matter of words but should be given reality by action. They are linked: involvement of those affected in the design and operation of a compensation scheme makes for the openness and transparency on which trust is based; openness and transparency in turn is demonstrated by the willingness to involve people meaningfully in decisions which affect them.

I was glad to hear that you would be personally engaged in speaking with campaign groups this week. I hope that your personal involvement leads to swift improvements; that from now on people infected and affected will be involved in the decisions that affect them, and that both they, and the public, will see from the results that the past is truly behind us.

Yours sincerely,

A handwritten signature in blue ink that reads "Brian J Langstaff". The signature is written in a cursive style and is underlined with a single horizontal line.

Sir Brian Langstaff

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