

Witness Name GRO-B

Statement No.: WITN1150004

Exhibits: WITN1150005-6

Dated: 19 March 2025

## INFECTED BLOOD INQUIRY

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WRITTEN STATEMENT OF GRO-B

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 10 March 2025.

I, GRO-B will say as follows:

**Please describe the involvement of people infected and affected in the decision-making regarding compensation (whether by Government or IBCA or both) as you have experienced it.**

1. I believe that the Government started off from a poor position at the very beginning. The previous Paymaster General, John Glen, announced on 8 February 2024 that the Government had appointed an expert group who would collectively advise the Cabinet Office on how best to respond to the Infected Blood Inquiry's recommendations on compensation. Professor Sir Jonathan Montgomery had been appointed Chair of this expert group. This group would essentially be advising the government on how the compensation scheme should operate.
2. My primary concern stems from the manner in which this group was selected and how the group made their decisions. The medical expert group advising

on aspects of the framework at the beginning were anonymous. The Scheme's foundations have been formed essentially by a secret committee; we did not know who was on the expert group, what decisions they made in forming their conclusions and we do not know what their experiences were. The government deliberately decided to act without involving the community or the representatives. There has been no transparency in the process.

3. I work as a GRO-B and from my experience to have proper engagement, the expert group should have involved both infected and affected people in those initial discussions, who would be able to voice their issues and concerns and provide their feedback and experience from the very beginning. Medical professionals do not see things from a patient's perspective; the experts were limited to only seeing the Scheme from the viewpoint of a clinician. There should have been proper community engagement from the outset as recommended by Sir Brian in the Inquiry Report.
4. The day after the publication of the Inquiry Report in May 2024, the Government published its already formed plans for the Compensation Scheme. Sir Robert Francis was announced as the interim chair of the Infected Blood Compensation Authority (IBCA) and undertook what were called "engagement meetings" on the proposed Compensation Scheme during the purdah period whilst the election was going on. It was said that this needed to be done 'at pace' to comply with the time limits in the Victims and Prisoners Act.
5. Sir Robert Francis put recommendations forward following criticism of the proposed Scheme during these "engagement meetings" although he acknowledged that he hadn't managed to speak to all of those in the Infected Blood community. As an infected person, I've not had an opportunity to engage nor have many others.
6. The Government's engagement with the campaign groups has been absolutely farcical. It wasn't a dialogue; it was a 4-minute window to say what you want and that is all. This is no way of engaging with people and in any event was pointless as the Schemes had effectively already been decided.

7. I am aware that members of the Haemophilia Society have met with officials from the Cabinet Office and they too have said it's been farcical. The way it been done is an absolute joke. They're not listening. They say that they have listened, but they haven't listened at all. They've decided what the Scheme is going to be – they then do an engagement exercise, but it's a tick-box exercise and no change has come about as a result of it.
8. What is more, when the IBCA/ Cabinet Office then reveal their decisions they can claim that they were made after hearing from different campaign groups. The reality is they're not listening. They've said they've listened, but they haven't listened at all. It feels as though people at IBCA have said 'we've got to do an engagement exercise so let's do one'.
9. It is systemically ill-considered and there has been a lack of proper engagement from the beginning. It has been set out in stone and after that they say we will now listen but we are not going to change anything.
10. In addition, IBCA does not have any autonomous decision-making authority. They are told that these are the rules and that is what you must do. There is therefore no value in contacting Sir Robert or IBCA.

**Please describe the principal concerns which you have in relation to the involvement of people infected and affected in the decision-making regarding compensation (whether by Government or IBCA or both).**

11. One of my principal concerns relates to how the Cabinet Office decided how the compensation scheme was to be formed. I mentioned previously that I have an interest in being kept informed on how the Compensation Scheme is developing and that I have attended webinars to listen to Sir Robert Francis and the IBCA. Whenever a question is raised by a member of the community which critiques or makes recommendations on the Compensation Scheme, Sir



Robert and IBCA adopt a particular line, which is that if anyone raises any criticism which relates to the content of the regulations, then we will have to raise our concerns with the Cabinet Office. We are told that the IBCA is only the mechanism by which compensation payments will be delivered. The IBCA is not independent and it has no autonomy at all. As much as David Foley and Sir Robert Francis say that they are distanced from the government – they are not. At the end of the day, who's drafting the legislation? The Cabinet Office. IBCA is the delivery tool – it is not independent.

12. I am also concerned that those who have designed the Scheme, including the Supplemental Route, and who are going to deliver it do not understand the Special Category Mechanism (SCM) and many who are eligible for higher payments through IBSS will not be eligible for the same under the Scheme.
13. The original guidance on SCM, which came out in August 2024, claimed that anyone who was entitled to SCM would automatically transfer across to the higher payment under the supplementary route but when they came about to proposing the legislation, they seem to have committed to a U-turn. I think this is absolutely farcical and a kick in the teeth for everyone who has relied on the guidance of IBCA.
14. Claimants who have previously met the IBSS eligibility requirement may be asked to obtain further additional evidence to qualify. I say further because previously, under IBSS, to receive a SCM payment you must have provided clinical evidence that was then signed off by a clinician.
15. Many IBSS recipients have had their clinical evidence approved by consultants who have around 20- or 30-years' experience. Now we're being asked to go back and find more information and even find more tighter rigor from other professionals to be able to be considered for higher payments.
16. Aside from the Cabinet Office contradicting themselves, my main issue with the approach adopted is that it seems to place an unnecessary burden on the claimants, and it also is inconsistent with the previous approach by the IBSS.

As I have said above, I believe this approach is systemically ill-considered and is a result of there being a lack of proper engagement with the infected blood community.

17. I wrote to the Paymaster General and the Cabinet Office on 5 March 2025 to communicate my concern in regard to changes made to the Scheme in respect of the SCM but have not yet received any response [WITN1150006]. The current draft regulations impose additional evidential requirements for claims under the supplementary route for the SCM.
18. One of the concerns I have relate to my personal circumstances. I was diagnosed with Myeloma in 2019. My diagnosis came about completely by accident; there was a conscientious haematologist who did a blood test to check something and incidentally my cancer was spotted. I am aware that there are clinical experts who assert that there is a risk that Hepatitis C causes Myeloma. I am also aware that there may be other people in similar circumstances. My oncologist has another patient who has had Hepatitis C and has also had a Myeloma diagnosis; there may be others out there who do not know and will not know until it's too late.
19. Neither the first nor the second set of Compensation Scheme regulations take Myeloma into account. I wrote to the Paymaster General and the Cabinet Office on 24 February 2025 [WITN1150005] to express my view; that its absence was a "grave oversight" and expressing my disappointment. I requested that the IBCA recognise the link between Myeloma and Hepatitis C, raise awareness of the link between Myeloma and Hepatitis C for the purposes of treatment and diagnosis and include Myeloma in the second set of infected blood compensation regulations. I also included links to public medical articles for their consideration and benefit.
20. This affects me on a personal level. I work as a GRO-B and I had aspirations of being a chief-executive of a hospital or at a minimum, a board level director. I was at a sub-board level employee when my Myeloma was diagnosed. I no longer have a career; now I just have a job. My role has

changed due to my illness; they think that, given my condition, that my previous role was causing me too much stress. My life expectancy is 30% of getting beyond 10 years. I've got two kids, and a wife and family. I am depending on the legislation taking into account what my career earning would have been had I not been infected with Hepatitis C. I feel like I'm being cheated and robbed.

**Are there any particular steps or measures which you consider could be taken by Government, IBCA or both to alleviate any detrimental impact upon people infected and affected? If so, please set them out.**

21. I think they need to listen to the concerns that the infected blood community have. I work in the health sector. One of the things is, if you listen to someone and you can't do something to help them, you tell them this and you tell them why you can't do it. This engagement should be a two-stage process: stage one is you listen to what is being suggested. Stage two is you say acknowledging what ideas you took on and what ideas you did not take on. We have not had any of this. Even if certain decisions are due to finances, they should at least be honest.

**Statement of Truth**

I believe that the facts stated in this witness statement are true.

Signed 

GRO-B
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Dated 19/3/2025

**Table of exhibits:**

<b>Date</b>	<b>Notes/ Description</b>	<b>Exhibit number</b>
24/02/2025	GRO-B to Nick Thomas-Symonds MP regarding concerns on the Infected Blood Compensation Scheme regulations	WITN1150005
05/03/2025	GRO-B to Nick Thomas-Symonds MP regarding concerns on the Special Category Mechanism	WITN1150006