

INFECTED BLOOD INQUIRY: 7-8 MAY 2025 HEARINGS

PRESENTATION:

EVIDENCE CONCERNING COMPENSATION

Introduction

1. Since late 2024 the Inquiry has been receiving increasingly concerned communications from individuals, organisations and legal representatives concerning the Government's and IBCA's approach to compensation. Those communications have contained expressions of distress, anger, frustration and despair which could not be ignored. The Inquiry sought to examine the position further, exercising its powers under rule 9 of the Inquiry Rules 2006 to request written statements. On 13 March 2025 the Inquiry published 27 witness statements describing these concerns. Further evidence was published on 9 April 2025, including witness statements from recognised legal representatives ("RLRs") who have had significant involvement with compensation issues. A small number of further statements have been received and will be published as soon as practicable.
2. The purpose of this presentation is to describe the principal themes and issues identified in this body of evidence. Each of the witness statements received by the Inquiry (at the time of writing)¹ are referenced within the presentation, though not in relation to each theme and issue. The presentation does not seek to summarise all of the many concerns described in the statements, and it is not intended to be a substitute for reading the statements themselves. Instead, following a summary of each theme or issue, it sets out non-exhaustive examples of the concerns raised, primarily using the witnesses' own words.
3. This presentation focuses on the evidence received from individuals, organisations and RLRs. It does not describe the evidence the Inquiry has obtained from Nick Thomas-Symonds (the Paymaster General), James Quinault (the director general

¹ These statements are listed in the Appendix to this presentation.

responsible for work within the Cabinet Office on infected blood compensation) and David Foley (Interim Chief Executive of IBCA), which will be explored during the hearings on 7-8 May 2025.

4. Whilst the presentation refers expressly to only a handful of the multiple letters and emails received by the Inquiry, each of those communications has been carefully read and considered. They raise the same (or very similar) concerns as those set out in the written statements referred to below.
5. The themes and issues described below are as follows:
 - i. Elation to despair
 - ii. Impact of ongoing compensation battles
 - iii. Delay
 - iv. Lack of transparency in criteria for inviting people to claim
 - v. Lack of involvement in decision-making
 - vi. IBCA engagement
 - vii. Engagement on prioritisation of claims
 - viii. User consultants
 - ix. IBCA as an Arm's Length Body
 - x. Repeating the mistakes of the past
 - xi. Communications from IBCA
 - xii. Importance of legal support and barriers to it
 - xiii. Mistakes in calculating awards
 - xiv. A "gagging clause"
 - xv. Burden of proof
 - xvi. Appeals
 - xvii. Compensation for hepatitis infection
 - xviii. The 31 March 2025 cut-off
 - xix. Position of affected children, parents and siblings
 - xx. Anomalies in the Regulations, care awards and financial losses related to infection in childhood
 - xxi. Unethical research
 - xxii. Impact on campaigning and support groups

- xxiii. Psychological support
- xxiv. Estate claims
- xxv. Proposed changes to the scheme.

Elation to despair

6. A theme which emerges vividly in the evidence received by the Inquiry is the contrast between the elation felt by many on the day the Inquiry's Report was published on 20 May 2024, and the anxiety and despair felt in the days following the Government's announcement of the compensation scheme on 21 May 2024 and the general election the following day.
 - a. Nicola Leahey: *"The long-awaited Final Report was delivered on 20th May 2024, it was such a relief that finally the truth was out there, and our plight was recognised. The feelings of the whole community was emotional, jubilant, and euphoric. We felt free of the burdens we had carried, we felt listened to, we felt justice! Little did we know that during the following days we would plummet yet again into despair and anxiety of the unknown. Not only did we have the uncertainty of our health and grief for those who had died during this long campaign but now we had the turmoil of the compensation details that were appearing."*²
 - b. Glenn Wilkinson of the Contaminated Blood Campaign: *"On the day of the release of Sir Brian Langstaff's Infected Blood Inquiry report, people were elated to finally feel that everything they had been saying for decades had finally been vindicated publicly however, in the days following the 20th May, the mono Hepatitis community in particular felt deceived and betrayed by Government and its departments. The impact this has had on the community was, and continues to be profound."*³
 - c. Alan Burgess and an anonymous witness on behalf of the Birchgrove Group: *"On 20 May 2024, along with thousands of other infected and affected victims, we attended the unveiling of the Inquiry's Report at Central Hall, Westminster. We were overjoyed with the Inquiry's findings and Sir Brian's comments; we finally felt vindicated after decades of campaigning — the truth had finally*

² Third Written Statement of Nicola Leahey WITN0223015 §2.

³ Second Written Statement of Glenn Wilkinson WITN2050115 §14.

been published. Our joy was short-lived; not because on 21 May 2024 the Government announced that it would compensate victims, but because of the document which they published that same day, titled "Infected Blood Compensation Scheme Proposal Summary"".⁴

Impact of ongoing compensation battles

7. One of the most striking themes in the evidence is the strength and depth of feeling amongst people infected and affected, including stress, anxiety and despair. Exhaustion is a common theme, including amongst those who had believed that – after decades – the need to campaign and fight had come to an end with the publication of the Inquiry's Report and the Government's acceptance of the need for compensation. Some report that the levels of distress have never been as bad as they are now.
 - a. Carol Grayson of Haemophilia Action UK: *"It feels as if we are waiting to die, in limbo, unable to make any progress in our lives and fearing as our health declines we may not ever get the compensation awards we deserve."*⁵
 - b. Denise Turton: *"It has been very stressful and quite overwhelming. ... I did have hope but that has gone and I am just exhausted with it all."*⁶
 - c. Glenn Wilkinson of the Contaminated Blood Campaign: *"we were looking forward to being able to start the process of closure and healing and attaining a level of peace whereby we could start to move on with our lives. Instead, we are left feeling that age and illness are catching up with us; there is no rest, there is no peace ... One of the consequences of campaigning at this level and at this intensity, is that it also has a devastating impact on our home and family life."*⁷
 - d. An anonymous witness from The Forgotten Few: *"Detrimental doesn't even scratch the surface. I've spoken with four or five of the regular people who I'm in touch with and they are all saying the same thing. They are almost in tears down the phone; you can hear the anger and despair in them. It doesn't even feel like one step forward, two steps back — it just feels like they've taken*

⁴ Written Statement of an anonymous witness W1387 & Alan Burgess WITN7752001 §§2-3.

⁵ Fifth Written Statement of Carol Grayson WITN1055207 §16.

⁶ Third Written Statement of Denise Turton WITN1575049 §18 and §22.

⁷ Second Written Statement of Glenn Wilkinson WITN2050115 §10.

*twenty steps back. Everyone feels stressed and anxious, this is why it feels as if we're back to the MacFarlane Trust days.”*⁸

- e. Mary Grindley: *“The mood now is one of anger, frustration, despair, stress, and disbelief again. We have been made to feel like second class citizens once again. We cannot take this anymore. ... I personally feel on the verge of another breakdown. I have difficulty sleeping and my brain is constantly whirling around. I try to distract myself from the situation with various activities, but it is impossible not to have the situation in the back of my mind all the time. I am nearly 76 and not in good health so I want to settle my affairs as soon as possible but, at the moment, I do not see the light at the end of the tunnel.”*⁹
- f. Ben Harrison of Milners Solicitors: *“Whilst writing this statement, I received a call from a campaigner who said to me that he could not remember community members ever being at such a low and that some had even reported feeling suicidal. This is remarkable when one thinks of what the community has had to endure over the past decades.”*¹⁰
- g. Samantha May of the Hepatitis C Trust: *“We have been dealing with newly diagnosed individuals and the existing infected blood community. I can confirm that the distress and confusion of both these groups, by which I mean ranging from an individual that has been newly diagnosed, to somebody who is well versed, engaged and has been campaigning about the issue for 30 or 40 years – the distress and confusion for everyone in the community is off the scale. And like nothing we have heard or seen before.”*¹¹
- h. Joyce Donnelly and Tommy Leggate of the Scottish Infected Blood Forum: *“The impact is that people feel they are being abused by Government all over again. People feel the abusers i.e. Government, and specifically the Cabinet Office, have substantively been left to decide the remedy for their own historic abuse. This has traumatised the infected and affected community even further. The Government know these people are vulnerable, sick and aging and yet operate their activities in ways that exacerbate peoples’ anxiety, mistrust, fear, revulsion, anger and despondency. The ‘working at pace’ lie that was*

⁸ Third Written Statement of an anonymous witness W1791 WITN1791047 §34.

⁹ Second Written Statement of Mary Grindley WITN2336029 §§57-58.

¹⁰ Written Statement of Benjamin Harrison WITN7759001 §126.

¹¹ Third Written Statement of Samantha May WITN0912009 §24.

continually peddled by Ministers has further traumatised people in our community.”¹²

- i. Andrew Evans of Tainted Blood: *“I cannot recall a time within the past twenty years that Tainted Blood has been active that we have experienced such overwhelming emotional drainage as has been the case since the compensation scheme was first announced on 21st May 2024. It is not an understatement to say that, alongside many members of the community, our Steering Group has been thrown into utter despair...”¹³*

Delay

8. One of the most central (and near universal) themes in the statements¹⁴ is the delay in compensation being delivered, the lack of any clear timescales as to when it will in fact be delivered, and the impact of this uncertainty.

- a. Carolyn Challis: *“The impact of the delays on the community has been devastating. We're suffering from compounded trauma, anger, frustration, exhaustion, and a loss of hope. We're experiencing an even further decline in our physical and mental health; I have heard several reports of individuals who feel suicidal. We don't feel heard, and it's as if there is contempt towards us. We have been left confused by conflicting and incorrect information and moving goalposts.”¹⁵*

- b. Nigel Hamilton of Haemophilia Northern Ireland: *“The biggest impact is the devastating delay... Victims are confused, bewildered and frightened as they wait for their compensation to begin its process, not knowing where they are or will be in the timeline. The distress of loss and bereavement becomes acute, and the torture pertains. The need for justice alienates them from Government and the IBCA and drains their confidence in a process that seems bereft of reasonableness in time and understanding of circumstances. The ongoing long-term sense of victimhood can become stifling. I assume a weight which*

¹² Second Written Statement of the Scottish Infected Blood Forum WITN7165016 §24.

¹³ Fourth Written Statement of Andrew Evans WITN1213015 §15.

¹⁴ These concerns feature prominently in the multiple emails and letters that have been sent to the Inquiry which also cover the likelihood that delay for elderly recipients will mean that more compensation is clawed back as inheritance tax when the initial recipients die.

¹⁵ Third Written Statement of Carolyn Challis WITN0622013 §20.

*only depresses and overpowers with resentment, emotional and psychological distress.”*¹⁶

- c. Sue Threakall: *“We are in complete despair over [the projected timetable for paying out claims], as many of us will not live long enough to see our final award paid out, let alone being well enough to use the money as we would have wished.”*¹⁷
- d. Colin Midgeley: *“My mum has cancer and is on borrowed time. The government knows that the longer they wait to pay out the compensation, the more people will die and the less money they will have to pay. My mum needs and deserves her compensation now, not in 2029. The doctors have told her she has between one and three years, potentially five if she is extremely lucky. People don't have the luxury of time to wait any longer for their compensation. My mum needs to be in a nursing home. She can't cook for herself; she struggles to walk and is in constant pain. When my mum first got her cancer diagnosis, she went into the nursing home. She is back home now because we cannot afford their fees. My mum has spent her life looking after the family, her sons and my dad. Now mum needs help, there is none.”*¹⁸
- e. Michael Imperato of Watkins & Gunn Solicitors: *“The single biggest source of anxiety amongst the infected and affected community is the length of time which it is taking to begin to process claims of any number. A number of clients contacting us are clearly traumatised by this. The common assumption is that it is a deliberate tactic so that numbers of victims will tragically die before their claims come to be considered.”*¹⁹
- f. Glenn Wilkinson of the Contaminated Blood Campaign: *“CBC members have been consistently asking for a timescale setting out when they can expect to receive their compensation so that they can manage their financial affairs.”*²⁰
- g. Danielle Mullan: *“Another big concern is that affected people seem to be “at the back of the queue”. I find this very worrying. Affected people's claims will die with them. Therefore, there may be many quite elderly and ill “affected persons” that will never see any compensation because they will die before*

¹⁶ Second Written Statement of Nigel Hamilton WITN2340014 §§63-64.

¹⁷ Letter from Sue Threakall to Sir Brian Langstaff SUST0000001 p3.

¹⁸ Second Written Statement of Colin Midgeley WITN3968002 §5.

¹⁹ Written Statement of John Michael Imperato WITN7761001 §64.

²⁰ Second Written Statement of Glenn Wilkinson WITN2050115 §23.

their cases are considered ... Also it seems very odd that they don't take families as a unit. Affected victims will normally be associated with an infected victim. Surely it will be easier to deal with them together at roughly the same time."²¹

- h. An anonymous witness from the Tainted Blood Widows Group: "... the glacial pace of IBCA to start even registering the affected led many affected widows (and parents) to fear they will never see their compensation".²²
- i. Alan Burgess and an anonymous witness on behalf of the Birchgrove Group: "Some people are scared that they won't be compensated in time to utilise their awards to ensure that they are able to enjoy what is left of their lives. Some people are scared that they won't be compensated in time to put their affairs in order and ensure that there is provision for their families once they are gone. Some people are scared that they will need to fight for another decade or more just to get what Sir Brian said they should get ... All any of us want now, is to be paid our compensation and to be left alone to get on with the rest of our lives."²³
- j. Cyrlia Knight of Saunders Law: "As the Inquiry will recall, my clients were four men living with haemophilia during the hearings. Of this cohort, all contracted HIV and hepatitis C through infected blood, one has very recently died. He had submitted his application under the IBCA and was awaiting disbursement when he died ... My client had spent time and effort before he passed away, likely during periods of illness, to draft and submit his claim. His children now must wait an unknown period of time before they must begin the application process again."²⁴

Lack of transparency in the criteria for inviting people to claim

- 9. A number of statements raise concerns as to the criteria for inviting people to claim and the lack of transparency as to those criteria. Linked to this is the uncertainty as to when the individual might themselves be invited to claim.

²¹ Second Written Statement of Danielle Mullan WITN2439002 §26.

²² Written Statement of an anonymous witness W7756 WITN7756001 §18.

²³ Written Statement of an anonymous witness W1387 & Alan Burgess WITN7752001 §§ 53 and 55.

²⁴ Written Statement of Cyrlia Knight WITN7767001 §§2 and 10.

- a. Samantha May of the Hepatitis C Trust: *“The Community wants a clear explanation about how 250+ people have been chosen at “random” and want information to spell out exactly what groups they have been drawn from for early claim offers.”*²⁵
- b. Carol Grayson of Haemophilia Action UK: *“I have no idea the names of the persons choosing the applicants to be compensated on Contaminated Blood or how they are chosen or what criteria is used; this is not transparency.”*²⁶
- c. Sean Cavens: *“I feel total despair. I feel that I am living in complete uncertainty and in limbo because I don’t know when I will be able to make a claim to the compensation scheme.”*²⁷
- d. Clair Walton: *“I have no idea when I will be able to make my claim for compensation and I have no idea when the scheme will open up to applications without invitation. This is the biggest source of anger and upset for everyone waiting to make their claim. More information needs to be given about anticipated timescales because as matters stand, we don’t know whether it will be two months or two years before we are able to make our claims.”*²⁸
- e. Gary Webster (on behalf also of other Treloar’s pupils Steve Nicholls, Richard Warwick and Adrian Goodyear): *“We cannot make any plans, we are in limbo and don’t know if and when we will get compensation so how do you plan, you cannot ... It is constantly on my mind, I worry what next, are we going to get the magic email or will it be the end of the year, we just don’t know. Why are they treating us like this?”*²⁹

Lack of involvement in decision-making

10. Lack of involvement in decision-making regarding the design and operation of the compensation scheme is a repeated theme in the statements provided to the Inquiry. This has plainly (both from the witness statements and from the many communications that the Inquiry has received) given rise to anger; to a sense of history repeating itself; and to the firm belief that the compensation scheme does not,

²⁵ Third Written Statement of Samantha May WITN0912009 §21.

²⁶ Fifth Written Statement of Carol Grayson WITN1055207 §22.

²⁷ Fourth Written Statement of Sean Cavens WITN1146047 §15.

²⁸ Fourth Written Statement of Clair Walton WITN1589029 §15 c).

²⁹ Second Written Statement of Gary Webster WITN1723044 §26.

in consequence of that lack of involvement, adequately meet the needs of people infected and affected.

11. An overriding concern is that the Government created a compensation scheme without the community's direct involvement, and that, aside from the short period of engagement undertaken by Sir Robert Francis straight after the announcement that led to people being able to choose to continue receiving support payments, it has not been possible to change important features following its announcement.

- a. Sean Cavens: *"While we were at the heart of the Inquiry, it feels like we are an afterthought and are now spectators in the process. This goes against the recommendations of the Inquiry, which highlighted the importance of the infected and affected being involved in the process of the design of the compensation scheme."*³⁰
- b. Glenn Wilkinson of the Contaminated Blood Campaign ("CBC"): *"CBC are not aware of anyone infected or affected being involved in the decision-making regarding compensation. It is clear that key decisions have been made by Government and IBCA on our behalf without our involvement ... Had the Government engaged with our community after the release of Sir Brian Langstaff's Second Interim Report on 5 April 2023, CBC feel the compensation scheme would have stood a far better chance of securing the confidence of the community which would have been ready to roll-out following the publication of the Infected Blood Inquiry Report. Had Government engaged with the community, we strongly feel that most, if not all, of the concerns which have been raised since 20th May 2024, could have been avoided."*³¹
- c. Andrew Evans of Tainted Blood: *"Given that the intention under the recommendations of the Inquiry was to involve the scandal's victims, both infected and affected, in decisions surrounding the formulation of a compensation scheme, we were disheartened to learn that the scheme had already been devised well in advance of the announcement on May 21st, with little to no input from the infected blood community."*³²

³⁰ Fourth Written Statement of Sean Cavens WITN1146047 §11.

³¹ Second Written Statement of Glenn Wilkinson WITN2050115 §§6-7.

³² Fourth Written Statement of Andrew Evans WITN1213015 §2.

- d. Danielle Mullan: *“What is of particular concern, is that it was stated in the Interim Compensation Report of Sir Brian Langstaff (April 2023) that victims and also victim lawyers should be involved in the setting up and monitoring of the scheme. I can remember our solicitor, Michael Imperato making this point at several meetings in Northern Ireland in 2023 and early 2024. However, that never happened. The Government began the process of setting up the scheme and its systems, in secret, before the publication of the Inquiry Report. There was no involvement of any victims, victim groups or their lawyers. It seems to me that the way the scheme is being run now is 'set in stone'. This means that there has been, and continues to be, no input from victims.”*³³
- e. Kate Burt of the Haemophilia Society: *“As far as the Society is aware, infected and affected individuals had no involvement in the decision making on the initial set up of the scheme or IBCA. These decisions were all made by the Paymaster General and the expert group, and simply communicated to the community in May 2024.”*³⁴
- f. Nigel Hamilton of Haemophilia Northern Ireland: *“The process is moving forward with little involvement from the infected blood community representatives at the critical stages and presents as a fait accompli with little to no opportunity to influence or change critical aspects of the process.”*³⁵

12. Some statements express particular concern over the role of the Expert Group – chaired by Sir Jonathan Montgomery – appointed to advise the Government on the design of the compensation scheme, including that it did not engage with people infected and affected, which was not permitted under its terms of reference.³⁶

- a. Bruce Norval: *“The Inquiry's second interim report made it clear that it was vital that the expert panels should engage with beneficiaries. There has been no such engagement. The clinical group informed the scheme without any consultation with the infected and affected community. This is undoubtedly where the primary errors and angst are flowing from. The Expert Group chaired by Jonathan Montgomery did not take into account all of the evidence*

³³ Second Written Statement of Danielle Mullan WITN2439002 §21.

³⁴ Fifth Written Statement of Katherine Burt WITN6392288 §23.

³⁵ Second Written Statement of Nigel Hamilton WITN2340014 §49.

³⁶ The reasons for that lack of engagement – the terms of reference of the Expert Group – will be explored during the hearings on 7-8 May 2025.

obtained by the Inquiry and I therefore believe that it has made a number of flawed assumptions.”³⁷

- b. Bill Wright of Haemophilia Scotland: *“The problem, it appears, stems from two of the foundations for the compensation scheme as it has developed. Firstly, the Expert Group did not take evidence from those affected when drawing up its recommendations or consult them. The Government then based its proposed levels of payment on the Montgomery proposals. No rationale has ever been produced for the tariffs, particularly in relation to impact on health where the figures that have been used are round numbers. They do not appear to have taken account of the extensive evidence that was available to the Inquiry.”³⁸*
- c. John Dearden of Haemophilia Scotland: *“From the immediateness of the government response in May 2024 it was apparent that, behind the scenes, the government had been working with the Infected Blood Expert Group appointed by the Paymaster General in January 2024 to draw up the government's response to the Inquiry recommendations in the second interim report. All of this was with no consultation with the infected blood community, or regard to the involvement of the infected community in decisions which affect them as recommended by the Infected Blood Inquiry.”³⁹*
- d. Dr Justine Gordon-Smith: *“First, we have been excluded from any involvement in designing or being part of a compensation scheme. ... Secondly the expertise gathered together by Sir Jonathan, amounted to knowledge of specific viruses, and there was no one with expertise in Mental Health, or Social Care of infected blood victims, and no expertise in the lives of those affected.”⁴⁰*
- e. An anonymous witness: *“My primary concern stems from the manner in which this group was selected and how the group made their decisions ... 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.”⁴¹*

³⁷ Fourth Written Statement of Bruce Norval WITN2235014 §7.

³⁸ Fourth Written Statement of William Wright WITN2287087 §22.

³⁹ Written Statement of Haemophilia Scotland WITN7754001 §5.

⁴⁰ Third Written Statement of Justine Gordon-Smith WITN2632085 §§47-48.

⁴¹ Written Statement of an anonymous witness W1150 WITN1150004 §§2-3.

13. A related aspect of this lack of involvement in decision-making is that, where engagement has taken place by the Cabinet Office and IBCA, witnesses state that it has not been meaningful. This issue arises very frequently across the statements and correspondence received by the Inquiry, with one caller whose now elderly mother was infected with Hepatitis B and has received no support or compensation telling the Inquiry *“IBCA is trying to make you feel involved, but you’re not involved and nothing goes anywhere: they’re doing what they want to do, rather than listening and saying as a result of listening we’re going to do ...”*.

- a. Joyce Donnelly and Tommy Leggate of the Scottish Infected Blood Forum: *“SIBF’s Manager attended meetings with the Paymaster General and his Cabinet Office officials, including the Director General of the Cabinet Office, James Quinault, and his deputy, Robin Healey. Our Manager did not consider the arrangements around these meetings provided substantive or meaningful engagement, but merely lip-service and to rubber stamp an engagement process taking place. The appearance of being listened to was there but it transpired that the decision-making process had already been completed by Cabinet Office; we considered the meetings to be only a listening exercise by Government to allow them to tick a box and appear to engage substantively with the infected and affected community representatives.”*⁴²
- b. Stuart McLean: *“Despite my engagement with the Cabinet Office, IBCA and the Government, I have had little success in actually bringing about any change. I would describe attempts to communicate as like “banging our heads against a wall” because the IBCA is quite happy to sit in a meeting with campaigners but they aren’t actually listening to, or acting upon what we have to say. I am not satisfied that we had sufficient involvement in the decision-making process. While we were given the opportunity to attend meetings, these were usually short and failed to engage with us meaningfully, I have always been left with the feeling that decisions had already been made and that the consultation was just for show.”*⁴³
- c. Samantha May of the Hepatitis C Trust: *“... it soon began to feel to the Community that this was just another tick box exercise that said “we have*

⁴² Second Written Statement of the Scottish Infected Blood Forum WITN7165016 §14.

⁴³ Second Written Statement of Stuart McLean WITN0653028 §§5-6.

*engaged with the community" but with little substance or clarity. Some in the group found it offensive and frustrating. We at the Hepatitis C Trust and the community expected much more active and wide-ranging involvement based on the recommendations in Sir Brian's second interim report and final report from both IBCA and CO."*⁴⁴

- d. Gary Webster: *"Quite simply we have at no point been involved in decision making. We are effectively presented with a fait accompli and asked to comment. ... The lack of any real involvement of campaigners and their legal representatives in the decision-making process has been incredibly frustrating. It has left us feeling like we have been used and are being used again so IBCA and the Cabinet Office can say they have engaged with us in relation to its decision making when in reality they have only paid us lip service."*⁴⁵
- e. Lynne Kelly of Haemophilia Wales: *"The record will show that there has been a generous allocation of Government staff time to the numerous meetings scheduled out in my submission. However, hosting a meeting is not necessarily a consultation unless proposals/ideas/issues are tabled for discussion, and not already been decided, in secret, in advance. It is therefore fair to say that there has been no meaningful consultation or engagement and therefore no involvement in any part of the decision-making process. It cannot even be said that the questions tabled, led to discussion which informed decisions as the questions were not responded to: "We are waiting for direction from the Cabinet Office"."*⁴⁶
- f. Owen McLaughlin of TB: Affected Siblings & Children: *"my experience has not been one of involvement but of being kept at arm's length. Legitimate offers to contribute have gone unanswered. Genuine concerns have been brushed aside with vague or technical responses. Key decisions appear to have been made behind closed doors, with limited transparency and no structured inclusion of those most affected. The process, as it stands, feels top-down, disconnected, and too often blind to the realities faced by the people it is supposed to serve."*⁴⁷

⁴⁴ Third Written Statement of Samantha May WITN0912009 §36.

⁴⁵ Second Written Statement of Gary Webster WITN1723044 §13 and §21.

⁴⁶ Second Written Statement of Lynne Kelly WITN3988094 §47.

⁴⁷ Second Written Statement of Owen McLaughlin WITN7766001 §10.

- g. An anonymous witness: "... 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."⁴⁸

14. One illustration of witnesses' concerns regarding the Government's lack of meaningful engagement relates to meetings with the Paymaster-General in December 2024, at which attendees were each allocated a few minutes to speak.

- a. An anonymous witness from the Tainted Blood Widows Group: "*I met with the Minister on 11 December. There were four campaigners in the meeting. We were each given 4 minutes in which to speak and put our concerns. In order to do this, I had to write out the headings of the matters I needed to raise, then time myself with a stopwatch to see if I could say it all. I had to speak like a horse racing commentator to get it all in. This is not a meaningful engagement!*"⁴⁹
- b. Richard Newton of TB: Affected Siblings & Children: "*We then had a meeting with Nick Thomas-Symonds on 18 December with seven other campaign groups but I was told the day before that I only had 4 minutes to speak. How am I supposed to do that? How am I supposed to represent the concerns of all of the people in my group. It's disgusting. It's not engagement.*"⁵⁰
- c. John Dearden of Haemophilia Scotland: "*This was the first opportunity to speak directly with the Minister since his appointment in July 2024. In reality each representative had only about 5 minutes to make any points they wished to raise. We regard this lack of direct engagement for so long on such an important issue as appalling. To expect each representative to speak for only five minutes is an unbelievable affront to the people we represent.*"⁵¹
- d. Colette Wintle: "*I don't think the Cabinet Office and its officials comprehend how disrespectful this appears to the community given we are supposed to be at the heart of all decisions taken which will affect what is left of our lives.*"⁵²

⁴⁸ Second Written Statement of an anonymous witness W1150 WITN1150004 §21.

⁴⁹ Written Statement of an anonymous witness W7756 WITN7756001 §22.

⁵⁰ Second Written Statement of Richard Newton WITN6897002 §26.

⁵¹ Written Statement of Haemophilia Scotland WITN7754001 §34.

⁵² Letter from Colette Wintle to Sir Brian Langstaff CWIN0000052 p2.

IBCA engagement

15. Some of the evidence received by the Inquiry is more positive about engagement with IBCA than the Cabinet Office, but an important theme is that IBCA is unable to provide answers or make meaningful changes without seeking direction from the Cabinet Office.

- a. Andrew Evans of Tainted Blood: *“Whilst there have been some efforts to engage with us by both IBCA and the Cabinet Office, we feel that these engagements are largely tokenistic, to satisfy the appearance of engagement rather than in order to make substantial changes to the scheme based upon our recommendations. Having said that, I do not place IBCA in the same category as the Cabinet Office. IBCA, whilst heavily restricted by policy, appears to be making the right efforts to achieve its remit as designed by the Cabinet Office, and has actively listened to us. However many of their answers to our concerns can be summarised by a deference to the policy team at the Cabinet Office; ergo, these concerns are not within their power or remit to make the necessary changes. To put it simply, there is a significant amount of buck-passing.”*⁵³
- b. Joyce Donnelly and Tommy Leggate of the Scottish Infected Blood Forum: *“Meetings with Government and Cabinet Office are strictly controlled and managed by them. Our experience with IBCA's engagement is substantively better than this. There have been several occasions where there were protracted lags in email communications, and we feel that was in part due to capacity issues within the organisation as it continued its fledgling existence. These communication issues have dissolved over time and our Manager has had some favourable exchanges with IBCA directors, as well as its Chair and Chief Executive, where we felt we were being listened to and positively engaged with. However, IBCA's hands are tied by its remit from Cabinet Office and decision-making with them is limited to operational matters of the compensation scheme, which has been designed and managed by Cabinet Office officials. To that extent it is not a true Arms-Length Body in the spirit of the Inquiry's report.”*⁵⁴

⁵³ Fourth Written Statement of Andrew Evans WITN1213015 §§10-11.

⁵⁴ Second Written Statement of the Scottish Infected Blood Forum WITN7165016 §§18-19.

- c. Samantha May of the Hepatitis C Trust: *“The IBCA staff do engage more than the CO, but their hands seem tied. They are now trying to engage, albeit too late, and simply appear impotent, as they cannot provide any answers and say they cannot make any changes. That is of no use to the Community. What is the point of speaking with the Community if, as an organisation such as IBCA, you have no power to make any changes. The CO is simply deflecting to IBCA.”*⁵⁵

Engagement on prioritisation of claims

16. One issue on which IBCA has sought the views of the infected blood community concerns the order in which groups should be invited to make claims under the scheme. Several witnesses describe this as an inappropriate issue on which to consult, not least because it might lead to each group suggesting that it should be prioritised, and that it would result in divisions in the community.
- a. Clair Walton: *“On 16 January 2025, I attended a meeting virtually where the issue of sequencing invitations to claim (i.e. the order of prioritising invitations) was being discussed. I remember asking questions about why there had ever been a consultation with the ‘community’ in relation to the point when it seemed obvious that different factions would each argue that they ought to be prioritised. Also, that the process had been traumatising. The sequencing consultation had taken place prior to me taking up my role⁵⁶ and I had participated in the consultation and witnessed the damaging impact. I was told that the IBCA had to consult on such an important issue.”*⁵⁷
- b. Dr Justine Gordon-Smith: *“We also objected strongly, (and I made these points directly), in a meeting I attended with the Getting It Right Group on the 17th of December 2024, with Sir Robert, David Foley and Rachel Foster, that in November 2024, IBCA organised us into different categories of victims, and then asked us, who should be prioritised for compensation. I told them it was completely unedifying for them to take a community they know are divided and to then pit them actively against the other.”*⁵⁸

⁵⁵ Third Written Statement of Samantha May WITN0912009 §43.

⁵⁶ As a user consultant.

⁵⁷ Fourth Written Statement of Clair Walton WITN1589029 §14(a).

⁵⁸ Third Written Statement of Justine Gordon-Smith WITN2632085 §33.

- c. Gene Matthews of Leigh Day: “the 10 February 2025 update, confirms that IBCA sought the views of the Community as to which cohorts should be prioritised and why. This has caused the Community to be pitted against each other and exacerbated the historic arguments within the Community relating to whole blood and blood products. I am often told that individuals are reading messages on the campaign group Facebook pages and even the IBCA social media pages that suggest hierarchical levels of harm. This is wholly inappropriate and exemplifies the lack of engagement the IBCA has undertaken in respect of the Inquiry and its findings.”⁵⁹
- d. Ben Harrison of Milners Solicitors: “For reasons which I struggle to fathom, the IBCA began consulting with campaigners in Autumn 2024 on the order of priority in which claims should be invited. I struggled to fathom the reasons for this consultation because it seemed patently obvious that every campaign group representing infected people would naturally and understandably – perhaps even necessarily – advocate that their cohort should receive priority. In my opinion, this consultation did little other than cause further anxiety and anger amongst the infected community and served only to pit groups of infected people against one another whilst hinting that it may yet be some considerable time before applications without invitation would be accepted.”⁶⁰

User consultants

17. Concern is expressed in a number of statements regarding the appointment of user consultants by IBCA – suggesting that this is an inadequate or inappropriate substitute for more comprehensive engagement.

- a. Alan Burgess and an anonymous witness on behalf of the Birchgrove Group (commenting on an 8 January 2025 meeting with Sir Robert Francis and David Foley): “We next discussed the recent employment of User Consultants by the IBCA. Our view is that these are unnecessary positions which will serve only to generate anger and disunity amongst the infected and affected community: we asked what the User Consultants were being consulted upon and Sir Robert was unable to give an answer. The user consultant position bears

⁵⁹ Written Statement of Gene Matthews WITN7762001 §57.

⁶⁰ Written Statement of Benjamin Harrison WITN7759001 §§77-78.

remarkable resemblance to the user trustee positions that existed within the MFT and we had hoped that the IBCA would do all that it could to avoid comparisons with the Alliance House Organisations. We were left with the impression that the User Consultants had been employed for the mere purpose of adding to the veneer of engagement that the IBCA seeks to create.”⁶¹

- b. Gary Webster: *“Our group has serious concerns regarding the current appointment of 3 individual consultants by IBCA from within the infected/affected community. These people were not democratically elected to represent all. In fact, although highly knowledgeable of their particular circumstances, none have the authority to represent everyone. Most importantly, how can they when there is not a single haemophiliac amongst them? The selection and recruitment process seemed to be done underhandedly. This in our opinion is wrong, lacks transparency and is non-inclusive of the full representation of victims, especially as it leaves out a large and important cohort, i.e., directly infected haemophiliacs.”⁶²*
- c. Gene Matthews of Leigh Day (commenting on a meeting with IBCA, in which the proposed appointment of a single user consultant was discussed): *“We informed Sir Robert that, in our opinion, this should be several individuals from within the Community so all cohorts within the Community are represented. While the IBCA did go on to employ three individuals to the Communications Advisory Panel, to this day not all cohorts are represented. Unfortunately, it mirrors the approach taken by the Paymaster General Nick Thomas-Symonds who, following the Government's announcement regarding a Scheme, met with selected members of the Community only. Again, this did nothing but exacerbate the underlying concerns and mistrust felt by the Community.”⁶³*
- d. Benjamin Harrison of Milners Solicitors: *“On paper, I will readily accept that the concept of involving an infected and/or affected person in the IBCA's decision making is a good one but anyone familiar with the Alliance House Organisations will make an immediate comparison with the MFT's user trustees. I felt that this had at the very least, the potential to recall upsetting*

⁶¹ Written Statement of an anonymous witness W1387 and Alan Burgess WITN7752001 §27(c).

⁶² Second Written Statement of Gary Webster WITN1723044 §14.

⁶³ Written Statement of Gene Matthews WITN7762001 §26.

memories for many. Secondly, I think that those working with the Inquiry and infected and affected people on a daily basis saw that different factions of the infected and affected community did not always rub along together very smoothly. There are different (and at times, competing) interests amongst the community and I thought it quite naïve of the IBCA to consider that any one single person might be capable of commanding the acquiescence let alone the confidence of everyone.”⁶⁴

IBCA as an Arm’s Length Body

18. Many witnesses consider that IBCA is not in fact an Arm’s Length Body, at least not as intended in the Inquiry’s recommendations. Witnesses report that IBCA defers to or requires direction from the Cabinet Office whenever issues of any significance arise.

- a. Denise Turton: *“IBCA is not an arm’s length body no matter how many times they say it is. It still reports to the Cabinet Office and has to ask what they can and cannot say. We get the same replies to our letters, it’s just a different version of ‘the line to take’.”⁶⁵*
- b. Mary Grindley: *“... the Inquiry recommended that the Infected Blood Compensation Scheme be set up as an arm’s length body to the Government and Cabinet Office. This is, as a matter of fact, not the case. All of the individuals involved in the Infected Blood Compensation Authority are Cabinet Office staff and Civil Servants. To victims, these are the very same people who are responsible for the cover up of the infected blood scandal over decades and the appalling treatment of victims, evidence of which was heard in abundance by the Inquiry. Victims of contaminated blood should not be dictated to by the Cabinet Office.”⁶⁶*
- c. Sean Cavens: *“There is a lack of trust as the IBCA say that they are an Arm’s Length Body, but also say they have to report back to the Cabinet Office.”⁶⁷*
- d. Bruce Norval: *“The lack of independence of the scheme from Government due to it not being a proper Arm’s Length Body as recommended by the Inquiry*

⁶⁴ Written Statement of Benjamin Harrison WITN7759001 §32.

⁶⁵ Third Written Statement of Denise Turton WITN1575049 §23.

⁶⁶ Second Written Statement of Mary Grindley WITN2336029 §23.

⁶⁷ Fourth Written Statement of Sean Cavens WITN1146047 §12.

*shows that there has not been an acknowledgement that the Government is one of the biggest participants in the infected blood scandal. This is one of the things that victims are struggling with the most. I can see lots of issues impacting on the accuracy of claims being hidden behind the Regulations. The scheme says it's the responsibility of the Government while the Government says the scheme is an Arm's Length Body. My fear is that the unfairness becomes engrained in inadequacy.”*⁶⁸

- e. Lynne Kelly, Haemophilia Wales: *“Everything about IBCA seems to me to be determined by civil servants (and thus, the Government). It seems to me that IBCA is an agent of the Government. This was the concern and issue victims had with the Skipton Fund. On the 27th November 2024 at the meeting of what is called the IBCA Communications Advisory Panel, we were told that all decision making rested with the Cabinet Office.”*⁶⁹
- f. Kate Burt, Haemophilia Society: *“the specificity of the regulations is perceived to be a means in which the government is controlling the decisions to be made which in effect is resulting in IBCA being a version of the Infected Blood Support Schemes.”*⁷⁰

Repeating the mistakes of the past

19. As well as concerns about the extent to which the compensation scheme in fact implements the recommendations made by the Inquiry, a number of statements describe the Government and IBCA as repeating the mistakes of the past. This includes, for example, institutional defensiveness and the approach taken by the Alliance House organisations.

- a. Nicola Leahey: *“I fear that the same institutional defensiveness and groupthink that caused the original scandal's cover-up are now hindering the scheme. This raises concerns about further delays, inequities in compensation, erosion of trust, and compromised transparency.”*⁷¹
- b. An anonymous witness who supports people infected and affected: *“One thing I have found annoying is how IBCA people are saying how they are learning*

⁶⁸ Fourth Written Statement of Bruce Norval WITN2235014 §10.

⁶⁹ Second Written Statement of Lynne Kelly WITN3988094 §55.

⁷⁰ Fifth Written Statement of Katherine Burt WITN6392288 §45.

⁷¹ Third Written Statement of Nicola Leahey WITN0223015 §5.

*lessons every day, they shouldn't be learning lessons now, the lessons/mistakes of the past made by the McFarlane Trust and Skipton Fund and Alliance House entities, they have made the mistakes already so they shouldn't be making mistakes now, the jolly ha ha ha lessons learnt attitude has really annoyed a lot of people and upset people. Even last week on a webinar they were telling people they were learning lessons everyday. I am really sorry but this is not the time to be learning lessons, by doing this they are retraumatising very sensitive and traumatised damaged people and the longer this goes on the worse it will get, it will not get better the longer they hang this out.”*⁷²

- c. Alan Burgess and an anonymous witness on behalf of the Birchgrove Group: *“It is for all of these reasons that we describe the IBCA as the MFT on steroids. ... On 20 May 2024, we read the Inquiry's report and listened to Sir Brian's words in a state of almost disbelief: that after decades of fighting and campaigning, the truth had finally emerged, there was a common sense that the fight was over. From 21 May, the Government began to take that victory away and over the course of the last eight months, has taken us back to the days of fighting with the MFT at every turn.”*⁷³
- d. Lynne Kelly on behalf of Haemophilia Wales: *“many of the behaviours that brought about the need for a Public Inquiry remain ingrained in the Government's responses.”*⁷⁴
- e. Bill Wright: *“It appears that the door is being slammed shut on us whenever we raise relevant shortcomings. It feels similar to the obstructive approach we faced with Scottish Government in the early 2000s as highlighted and criticised in the Inquiry's final report...”*⁷⁵

Communications from IBCA

- 20. Several witnesses have raised concerns around communications from IBCA, including in relation to their clarity and tone.

⁷² Written Statement of an anonymous witness W7758 WITN7758001 §7.

⁷³ Written Statement of an anonymous witness W1387 and Alan Burgess WITN7752001 §§47 and 49.

⁷⁴ Letter from Lynne Kelly, Haemophilia Wales, to Sir Brian Langstaff LKEL0000010.

⁷⁵ Fourth Written Statement of William Wright WITN2287087 §19.

- a. Ben Harrison of Milners Solicitors: *“The updates which the IBCA provides to campaigners can be rather dense and, as I have said previously, impenetrable to a number of infected and affected people who contact me for interpretation. I have some sympathy for the IBCA in this regard because many of the updates, particularly those concerning the Regulations, are attempting to convey extremely complicated information which I can appreciate may be difficult to simplify to the requisite extent. However, many of the IBCA’s written communications often appear tone-deaf. A prime example is the regular updates that the IBCA has provided since December about the number of claims which have been invited, the number of offers of compensation which have been made and the total amount which has been paid out. Some of my clients have reported to me that they perceive these updates as self-congratulatory in tone which they consider to be wildly inappropriate given the lack of any apparent significant increase in the rate at which claims are being accepted by the IBCA.”*⁷⁶
- b. John Dearden of Haemophilia Scotland: *“Overall, a lack of transparency, poor communication, and limited engagement with the community have intensified feelings of distrust and isolation.”*⁷⁷
- c. Mary Grindley: *“The information being released periodically by the IBCA at the moment is extremely confusing and offers no clarity to victims.”*⁷⁸
- d. The Scottish Infected Blood Forum, Contaminated Blood Campaign and others (in a document entitled “Infected Blood Compensation: Getting It Right”): *“There needs to be more considerate use of language, particularly because these “words matter” because of the subject, and particularly when they are part of what appears to be the latest line to take. One current example is the use of “life-changing” to describe the anticipated amounts of infected blood compensation as if it applies to everyone. It is perhaps ironic that the same phrase, “life-changing”, is used by the Police to describe the more serious end of the spectrum of injuries that a victim of crime has sustained ... It was the infections that were life changing. In the attempted flip to positive, life-changing sounds more like a sound-bite spin phrase to pitch to an*

⁷⁶ Written Statement of Benjamin Harrison WITN7759001 §§83-85.

⁷⁷ Written Statement of Haemophilia Scotland WITN7754001 §76.

⁷⁸ Second Written Statement of Mary Grindley WITN2336029 §28.

*undiscerning media short on background fact checking. It has become an unwelcome and unhelpful trope that is akin to the previous disingenuous phrase, or lie, “working at pace.”*⁷⁹

- e. Owen McLaughlin of TB: Affected Siblings & Children: *“A particularly troubling example is the IBCA’s initial approach to defining a “registered estate.” It excluded cases where a bereaved partner, rather than the estate itself, had received interim payments via the Infected Blood Support Scheme, thereby omitting many of the longest-standing and most deserving cases. This exclusion caused enormous distress across the community, particularly for those who had already waited decades for justice. Following sustained pressure, the IBCA reviewed its position. However, it failed to acknowledge the harm caused and instead portrayed the change as a generous concession, publicly framing it as “based on your feedback, we’ve now expanded this to include more estates” rather than a correction of a serious and avoidable error. This episode encapsulates a wider pattern: decisions are made behind closed doors, harmful mistakes are spun as policy improvements, and there is little to no accountability when real people suffer as a result.*”⁸⁰

Importance of legal support and barriers to it

- 21. Many statements describe a lack of legal support and emphasise the importance of having access to the legal representatives who represented individuals during the Inquiry: they are trusted and deeply familiar with the issues and the background to individuals’ cases. A number of witnesses suggest that greater involvement from legal representatives could very significantly increase the speed at which IBCA delivers compensation.

- a. Timothy Wratten of The Fatherless Generation: *“...The Cabinet Office seem to have obstructed progress for funding reasons and seem to believe and have consistently argued that those infected and affected do not really need independent legal representation. ... This is absolutely not the case. Widows, children of the deceased, and infected people who are still dying need legal support with claims from the outset. They don’t have the time or strength to*

⁷⁹ Infected Blood Compensation: Getting It Right WITN7165021 pp24-25.

⁸⁰ Second Written Statement of Owen McLaughlin WITN7766001 §12.

*deal with new people or civil service bureaucracy and simply want the claims and any evidence in support to be put together by their chosen solicitor.”*⁸¹

- b. Sean Cavens: *“I feel that we are not being encouraged by the IBCA or the Government to have legal support. We rely on our lawyer's advice as they have assisted and advised us throughout the Inquiry process. We need our lawyers to be involved in the meetings and conversations with the Cabinet Office and the IBCA, and for them to be able to then communicate the information to their clients. This would increase trust in the process.”*⁸²
- c. Carol Grayson of Haemophilia Action UK: *“Our lawyers are very helpful, and we need them. They are important and valuable to us as they know our cases and the background to infections very well over several years now and most importantly, we trust them. They can explain difficult legal concepts and jargon and advise us regarding how and what we may be able to claim in compensation. However, we are worried that their role may be diminished due to the appointment of new case managers who don't know us or what we have experienced and are on a very steep learning curve in a very short space of time. It's important that our lawyers are funded adequately to continue to assist us on compensation issues. Our legal team provide support and a level of protection where there is existing "conflict of interest" they make life easier for us and we fear losing them.”*⁸³
- d. An anonymous witness from The Forgotten Few: *“I think the meetings would work better if they were being held with our lawyers assisting us. They have been by our side for the last 8 years and know all our stories and understand the legal issues. I feel that solicitors are the only real way to go forward to build confidence in the process. The short point is that we don't trust IBCA and the Cabinet Office, but we do trust our solicitors to act in our best interests. ... This [IBCA's claims system] seems to be an unnecessarily convoluted process and surely it would be simpler to allow the solicitors to prepare the necessary documentation and submit it with the necessary evidence. It would be simpler and quicker.”*⁸⁴

⁸¹ Second Written Statement of Timothy Wratten WITN1619006 §§4-5.

⁸² Fourth Written Statement of Sean Cavens WITN1146047 §16.

⁸³ Fifth Written Statement of Carol Grayson WITN1055207 §17.

⁸⁴ Third Written Statement of an anonymous witness W1791 WITN1791047 §35 and §38.

- e. Nigel Hamilton of Haemophilia Northern Ireland: *“I cannot understand why the process is that people are ‘invited’ to have their case considered, and the Case Manager starts off the case. Surely, it would have been far quicker for people to send in their applications, with key information/documents. Those of us who were CPs in the Inquiry have lawyers who have to hand, our Inquiry evidence. If that process had been adopted, hundreds of us would now have our cases ‘in the system.’ This is the biggest anxiety of victims, that they will not be invited to have their case considered for ages.”*⁸⁵

22. These concerns are reflected in the statements the Inquiry has received from RLRs. As well as noting the very significant amount of pro bono (i.e. unpaid) assistance they have given to people infected and affected since the Inquiry Report was published, related issues raised by the RLRs include a belief that IBCA and the Cabinet Office have not welcomed their involvement; that scheme applicants appear not to be encouraged to seek legal assistance; and the limited points at which RLRs are permitted to assist applicants.

- a. Danielle Holliday of Collins Solicitors: *“At a number of points in his statement Benjamin Harrison sets out that he felt that the involvement of RLRs was not welcome. I would go further and say that it was discouraged ... There is ... a complete refusal or inability to engage with the RLRs who have represented infected and affected people for years. ... It appears to me that a large part of the problem regarding the provision of legal support is again because the IBCA/Cabinet Office did not involve the RLRs in the process from the outset. It is also clear that they fundamentally do not understand the ethical and regulatory duties owed by solicitors to their clients. ... It would seem, from what we are told anecdotally, that applicants are not encouraged to seek independent legal advice at the outset even though it is provided at no cost to them. We are also aware that some of our clients have been told that we “may not have the capacity to assist”, that instructing a law firm “could lead to delays” and that claimants can rely on the claims manager to get all the information they need to bring a claim.”*⁸⁶

⁸⁵ Second Written Statement of Nigel Hamilton WITN2340014 §43.

⁸⁶ Written Statement of Danielle Holliday WITN7763001 §§42, 46, 60 and 104.

- b. Patrick McGuire of Thompsons Solicitors Scotland (describing concerns about the IBCA process): *“Firstly, there is a limited scope for legal advice. Legal representatives are only permitted to provide advice at two key stages: the declaration stage and the offer stage. This restriction means that claimants are navigating the process without legal support at other critical points. Given the complexity of the regulatory framework, there is a strong argument that broader access to legal advice would better protect the interest of claimants and ensure that decisions are properly scrutinised. Secondly, Issues with Documentation and Duplication of Effort. Applicants have been asked to provide documentation, such as medical records, that is already held by their legal representatives ... A more coordinated approach between IBCA and legal representatives would reduce the strain on applicants and improve overall efficiency. ... Thirdly, there are inconsistencies in Legal Representative involvement. There is a lack of consistency in when legal representatives are recognised by IBCA within the process. ... There has also been a perceived undermining of Legal Representation. There appears to be an implicit, if not explicit, position within IBCA that legal representation is unnecessary due to the availability of Case Managers. The publication of IBCA compensation calculators further reinforces this perception, as does the inconsistent signposting of legal representation throughout the application process. Claimants should be given clear and consistent information about their right to independent legal representation. This is particularly important given the complexity of the regulations governing IBCA compensation.”*⁸⁷
- c. Gene Matthews of Leigh Day: *“Overall, [commenting on a 17 September 2024 IBCA letter] I felt that the IBCA did not really wish to engage with the RLRs, and this was all but confirmed at the 2 October 2024 meeting during which the IBCA did not provide much detail in respect of the Scheme. ... I am not clear when individuals are informed that independent legal support is available, whether comments are or have been made by claims managers as to whether this legal support is necessary or that the legal support may slow or hinder the process and what steps are taken to ensure that legal support is provided promptly.”*⁸⁸

⁸⁷ Written Statement of Patrick McGuire WITN7760001 §§30, 31, 33 and 35.

⁸⁸ Written Statement of Gene Matthews WITN7762001 §§25 and 38.

- d. Ben Harrison of Milners Solicitors (commenting on developments in May-June 2024): *“The lack of engagement with RLRs struck me as incredible; between us, we knew and represented a vast number of infected and affected people – we were well placed to explain the implications of the Government’s proposals to our clients but were unable to do so efficiently because of this lack of engagement. Moreover, the IBCA and Cabinet Office would have saved themselves considerable time and effort had they engaged with us and enabled us to explain the proposals to our clients rather than having to field what I presume to be an enormous number of emails from scared and angry future claimants.”*⁸⁹

23. Consistent with statements from people infected and affected, RLRs have also suggested that their greater involvement could significantly increase the speed at which IBCA processes claims.

- a. Danielle Holliday of Collins Solicitors: *“We have suggested that it would be far more efficient and cost effective if we completed the Declaration Form with our client and submitted it to IBCA with supporting documentation, so we would effectively make the application on behalf of our clients. The claim could then be allocated to a claims manager who can arrange a call with the client and the legal representative to go through any queries before the client signs off the declaration. The claims manager could then produce an offer letter very quickly thereafter.”*⁹⁰
- b. Michael Imperato of Watkins & Gunn: *“There are many claims where the RLRs already hold all of the relevant records. It must be possible to speed up the process with the RLR taking on some of the front loading. Presumably that would also free up Claims Managers to deal with more cases at any one time. This point has constantly been put to IBCA and to the Government by RLRs and campaigners but to no avail.”*⁹¹
- c. Patrick McGuire of Thompsons Solicitors Scotland: *“In order to increase the number of claims that are being processed, in particular where documentation is held by RLRs from their representation of clients in the Inquiry, an*

⁸⁹ Written Statement of Benjamin Harrison WITN7759001 §12.

⁹⁰ Written Statement of Danielle Holliday WITN7763001 §130.

⁹¹ Written Statement of Michael Imperato WITN7761001 §66.

increased role could be given to legal representatives in the making of applications to the scheme. In circumstances where we do not have full records, we could recover these or liaise with IBCA. Where such documentation is held by legal representatives, they could be funded to collate the necessary documents and complete declaration forms. As well as meaning claims could be dealt with more quickly, this would reduce the need for clients to repeat information and provide documentation again, which minimises the re-traumatisation for applicants.”⁹²

Mistakes in calculating awards

24. Statements received from RLRs describe identifying errors in calculations by IBCA claims managers, and the important role that lawyers can play in correcting such mistakes.

- a. Danielle Holliday of Collins Solicitors (commenting on an IBCA letter of 20 February 2025 stating that “Nearly half of the claims processed so far contained all required details, including infection dates, diagnosis dates, and severity changes.”): “I can only assume that those claims were ones which were processed by claims managers alone, without any legal support, as we have found in the majority of claims we have dealt with the dates of infection and/or diagnosis were wrong and, in a number of claims, if left unchecked, would have resulted in under settlement of our clients' claims of between £20,000 and £160,000. I wonder whether this may be one of the reasons that there seems to be a reluctance to encourage individual claimants to seek independent legal advice. I pause here and accept that what I say may be slightly cynical but, having very nice claims managers who encourage claimants to trust them to input the correct information and not to seek free legal advice may lead to the processing of a large number of claims at an undervalue, which could potentially save the Government tens if not hundreds of millions of pounds.”⁹³

⁹² Written Statement of Patrick McGuire WITN7760001 §62.

⁹³ Written Statement of Danielle Holliday WITN7763001 §§89-90.

- b. Patrick McGuire of Thompsons Solicitors Scotland: *“The IBCA regulations are highly technical, and there have already been instances where Case Managers have misinterpreted them, leading to claimants receiving incorrect information. In at least one case, an error in IBCA's interpretation of the regulations would have resulted in an applicant's estate receiving substantially less than they had been advised in the event that their loved one chose to accept a particular offer and then died at a later date but before their Healthy Life Expectancy. The error was in relation to the case manager's interpretation of Regulation ... Fortunately, the claimant had sought independent legal advice, which allowed the error to be identified and rectified before a final decision was made. While these are genuine mistakes, their potential impact is severe. This reinforces the need for claimants to have access to independent legal advice throughout the process.”*⁹⁴
- c. Gene Matthews of Leigh Day: *“In addition, it has been reported to me that claims managers have in some instances provided the wrong information to individuals ... In one call, I was informed that a claims manager explained to an applicant that their financial loss award would be £12,000 per year; this is not the case. On the same call, the position in respect of Healthy Life Expectancy was incorrectly summarised. I am also aware that during an online meeting between an applicant, claims manager and a solicitor in my team, the claims manager was unable to explain the breakdown of the compensation to a degree which my client understood, despite her numerous questions. Following the call, my solicitor arranged a follow-up discussion to explain how the awards were broken down and how the compensation was calculated. On another occasion, a client understood that the heads of loss under the Scheme were optional, for example she believed that she would be offered the Autonomy Award following an assessment by the claims manager; she was not aware this was included in the Core Route as standard. I am also aware that in some instances the wrong infection date/year has been recorded in the declaration form. In one case the difference was five years, totalling £59,315 in compensation. If a solicitor in my team had not informed the*

⁹⁴ Written Statement of Patrick McGuire WITN7760001 §§36-37.

claims manager of the correct dates, there is no guarantee the position would have been known.”⁹⁵

A “gagging clause”

25. During the process of negotiating contractual arrangements for lawyers to support scheme applicants, a clause was proposed by IBCA/the Cabinet Office which would have restricted the lawyers’ ability to air criticisms in public. While the clause was subsequently amended, a number of witnesses have expressed their concern that it was ever proposed.

- a. Danielle Holliday of Collins Solicitors: *“On 21 December we, together with the other RLRs, received an email from David Foley attaching a letter and proposed variation to the contract to advise the next 250 claimants. It is fair to say that we were shocked and surprised (seems to be a common theme) at the attempt by the Cabinet Office to insert a clause which effectively prevented us from making any negative comments about the operation of the compensation scheme which we all considered may be detrimental to protecting the interests of our clients. [WITN7763016]. The RLRs agreed a response which was sent to David Foley on 23 December in which we set out in detail why the inclusion of what became known colloquially as the “gagging clause” would be in breach of our professional, ethical and regulatory obligations to each individual client. [WITN7763017]. We updated our clients on the position in a mail merge on 15 January [WITN7763918] and David Foley responded to the RLR letter of 23 December on 17 January [WITN7763019]. I cannot say whether the two are linked. He suggested an amendment to the clause which after some tweaking was acceptable to us all.”⁹⁶*
- b. An anonymous witness from the Tainted Blood Widows Group: *“Recently I learned that the Cabinet Office or IBCA had attempted to impose restrictions on the legal representatives in what amounted to a gagging order as a clause in their contracts. This was apparently to prevent them criticising IBCA and doing reputational damage. I said to James Quinault at the Cabinet Office that if all the legal representatives had banded together in an Operation Overlord*

⁹⁵ Written Statement of Gene Matthews WITN7762001 §46.

⁹⁶ Written Statement of Danielle Holliday WITN7763001 §§65-67.

style assault on the reputation of IBCA, they couldn't have done as much damage as IBCA themselves have done. It was an extraordinary own goal. Fortunately, they have now pulled back from this awful requirement.”⁹⁷

- c. Colin Midgeley: *“It's very hard to talk to people about what has happened. In the past we were told not to tell anyone. I believe that the government is trying to silence us again by trying to impose gagging orders on our lawyers.”⁹⁸*

Burden of proof

26. A number of statements raise concerns regarding the burden of proof under regulation 71 of the Infected Blood Compensation Scheme Regulations 2025, which puts the burden of proving any issue in connection with an application on the person making the claim, and the stifling effect that may have on genuine claims.⁹⁹

- a. Tainted Blood (in a document entitled “Tainted Blood Response to the Infected Blood Compensation Scheme: The community has, yet again, been let down”): *“Burden of proof once again on the victims The compensation scheme’s Statutory Instrument clearly states that the burden of proof will be on the applicant. This goes against the recommendations of both Sir Brian Langstaff and Sir Robert Francis.”¹⁰⁰*
- b. Nigel Hamilton of Haemophilia Northern Ireland: *“I have come to realise what a struggle it will be for victims to prove facets of their case ... I of course know my way around medical records and the like. I can also call on the help of clinicians ... I dread to think how victims without this experience and knowledge will cope.”¹⁰¹*
- c. Patrick McGuire of Thompsons Solicitors Scotland: *“Another concern that has frequently been expressed to us is the evidential requirements of the Scheme ... It has frequently been stated by IBCA and the Government that applications will be dealt with “sympathetically”, with no information about what this will mean in practice.”¹⁰²*

⁹⁷ Written Statement of an anonymous witness W7756 WITN7756001 §29.

⁹⁸ Second Written Statement of Colin Midgeley WITN3968002 §6.

⁹⁹ See by way of contrast the recommendations in the Second Interim Report at pp 37-39.

¹⁰⁰ Tainted Blood Response to the Infected Blood Compensation Scheme: The community has, yet again, been let down ANDE0000002 p3.

¹⁰¹ Second Written Statement of Nigel Hamilton WITN2340014 §29.

¹⁰² Written Statement of Patrick McGuire WITN7760001 §56.

- d. Michael Imperato of Watkins & Gunn: *“This issue is particularly acute in respect of transfusion cases. I am aware – through my institutional clients – of individuals who have attempted to register with both the support schemes and for interim estates payments through the Government. They have been rejected by both due to lack of determinative medical evidence. When they contact IBCA for an infected blood interim estates payment, they are refused because they are not with an existing blood support scheme, but when they have applied to a support scheme, they are refused because the medical records don’t exist ... No one wants a fraudster to succeed, but there appears in play here ... the ‘defendant lawyer mindset’. The issue might not be quite so troubling if there was an appeal system providing assurance, but there is not.”*¹⁰³

Appeals

27. In addition to the importance of legal support in the compensation scheme, witnesses have described concerns relating to the arrangements for appeals against IBCA decisions.

- a. Lynne Kelly of Haemophilia Wales: *“I am very concerned about the appeal process, which appears to have been given little thought and certainly no engagement. The proposed 1st Tier appeal process is also a cause for concern as if the application is unsuccessful, applicants will not have any funding for legal support to take appeals forward. When I asked about this at the meeting with James Quinault on 20th January, he said that appeals panels/judges were being trained. How much is all of this costing? If our lawyers were representing us, then claims would be settled fairly and quickly. .. In his recommendations, Sir Brian emphasised the need for a Specialist, Independent Appeal Tribunal. There is no sign of this.”*¹⁰⁴
- b. Michael Imperato of Watkins & Gunn Solicitors: *“In his second interim report, Sir Brian painted a picture of an appeal process recognisable to me from my experience with CICA claims and the Criminal Injuries Compensation Tribunal (CICT). Sir Brian recommended a bespoke, specialist*

¹⁰³ Written Statement of Michael Imperato WITN7761001 §73.

¹⁰⁴ Second Written Statement of Lynne Kelly WITN3988094 §§56-57.

panel, similar to the CICT. The CICT only hears CICA appeals, nothing else. Even though, at times, I might not have agreed with a CICT judgement, I wholly accept that they are a specialist panel and always took great assurance from that. In contrast, IBCA appeals are to be decided by the Social Security and Child Support Tribunal. According to the Government website of this Tribunal it deals with twenty-two different matters (not including infected blood) ... I personally find it extraordinary that Sir Brian's recommendation in this respect has been ignored. It is something of great concern and anxiety to my clients.”¹⁰⁵

Compensation for hepatitis infection

28. A theme which resonates throughout a number of statements (and is reflected in many of the communications which the Inquiry has received) is the concern that the scheme fails adequately to recognise Hepatitis C related conditions/the impacts of infection with Hepatitis C and of the treatments for Hepatitis C. This is seen to be a consequence of the lack of involvement of people infected and affected in the design of the scheme.

- a. Stuart McLean: “... *They have failed to grasp the severity of HCV as a life-threatening condition. For example, my good friend Pete Burney, despite clearing HCV and undergoing a liver transplant, still died fighting for justice; his case shows that clearing the virus doesn't mean that you are not at risk. I do not believe that having Hepatitis C for over 30 years and the harm that this causes individuals is being recognised by the compensation scheme. ... when we were infected as children, we were either treated with drugs that were experimental and had damaging side effects, or our infections were hidden from us for decades, making the damage done now irreparable ... I have reached the regrettable conclusion that the IBCA, Government and Cabinet Office has deliberately set out to play down the seriousness of Hepatitis C.*”¹⁰⁶
- b. Bruce Norval: “*The Expert Group chaired by Jonathan Montgomery did not take into account all of the evidence obtained by the Inquiry and I therefore believe it has made a number of flawed assumptions. For example, there has*

¹⁰⁵ Written Statement of Michael Imperato WITN7761001 §§60, 61 and 63.

¹⁰⁶ Second Written Statement of Stuart McLean WITN0653028 §§17-19.

been a failure to take into account exposure to blood products in childhood, a failure to take sufficiently into account the extra hepatitis manifestations of hepatitis C and a failure to recognise the ongoing effects of treatments for hepatitis C."¹⁰⁷

- c. David Leadbetter, Mono HCV Infected Haemophiliacs: *"How can it be that the shaping of a scheme, 50 years overdue, can take place without the presence of someone that specifically understands what we haemophiliacs have been through ... HCV infected haemophiliacs were treated repeatedly, not just once but time and time again with contaminated commercial Factor VIII at a time when it was widely known these products were infected with non-A non-B hepatitis and HIV. This was both negligent and reckless. Most of us were infected as infants so have never experienced life without hepatitis."*¹⁰⁸
- d. Carolyn Challis: *"Many extra hepatic manifestations will be hard to evidence. Most of us suffered in silence, having been fobbed off by doctors, or left mistrustful of the medical profession (we'd been poisoned after all!) and most will struggle to prove their cases."*¹⁰⁹
- e. Joan Edginton: *"All through the many years of trying to get my "non specific" symptoms acknowledged and treated I met the phrase "no clinical evidence" ... It was experts you called to the stand that could confirm the severity and damage done by the early treatments and yet here we are dealing with a compensation formula that completely ignores these factors or sets the bar so high and within a very narrow limit of type of illness that yet again too many are excluded."*¹¹⁰
- f. Glenn Wilkinson, Contaminated Blood Campaign: *"The complexity and unfairness within the Government's proposed scheme will mean that the time it will take to deal with mono Hepatitis claims will lead to huge delays thereby denying this cohort access to compensation in a fair and timely manner ... the overly burdensome and complex criteria being applied to all mono Hepatitis victims should be removed with immediate effect."*¹¹¹

¹⁰⁷ Fourth Written Statement of Bruce Norval WITN2235014 §8.

¹⁰⁸ Written Statement of David Leadbetter WITN7765001 §§12-13.

¹⁰⁹ Third Written Statement of Carolyn Challis WITN0622013 §26.

¹¹⁰ Email to the Inquiry from Joan Edginton. Joan gave evidence on 3 May 2019 INQY1000004.

¹¹¹ Second Written Statement of Glenn Wilkinson WITN2050115 §§33-34.

- g. Samantha May of the Hepatitis C Trust: *“One of the main issues that is most distressing for the Community, and for which we cannot provide an answer is why there is such a large discrepancy between the way people with HIV and people with HCV are treated in terms of compensation. We are trying to understand where the discrepancy lies to enable us to work out whether there is a reasonable comparison. This difference in payments and the banding appears to have come about from the Expert Group, which operated behind closed doors — initially without even the names of members being public. It did not involve the community, and the discussions of this group have never been made public, so there’s nothing on record that explains the discrepancies. The community simply do not understand why the CO did not use the experts that had given evidence to the inquiry.”*¹¹²
- h. The Scottish Infected Blood Forum, Contaminated Blood Campaign and others (in a document entitled *“Infected Blood Compensation: Getting It Right”*): *“The extremely discriminating failure to achieve realistic parity of tariffs between infecting viruses and impacts is causing great distress and anger within the community. Put simply, it seems that the terrible consequences of HIV infection are to be recognised, which is undeniably the right thing to do, but the correspondingly terrible consequences of Hepatitis infections are not being recognised to anything like the right apportionments ... People with Hepatitis have also progressed to advanced symptomatic hepatic disease including liver cirrhosis, liver cancer, transplant problems, and many other incurable and lifelong conditions.”*¹¹³
- i. Patrick McGuire of Thompsons Solicitors Scotland: *“A major concern is that the scheme as currently constituted does not sufficiently compensate those who are infected with Hepatitis C, due to the focus of the severity banding on liver damage. The scheme fails to take into account the many non-liver related consequences of Hepatitis C infection, including the impact of treatment, as reflected in the evidence heard by the Inquiry.”*¹¹⁴

29. Particular concerns have been raised (both in the witness statements and the many emails and letters received by the Inquiry) in relation to the replacement for the

¹¹² Written Statement of Samantha May WITN0912009 §38.

¹¹³ Infected Blood Compensation: *Getting It Right* WITN7165021 pp.6-7.

¹¹⁴ Written Statement of Patrick McGuire WITN7760001 §51.

Special Category Mechanism (“SCM”) and equivalent payments available through the Infected Blood Support Schemes.

- a. An anonymous witness: *“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 a U-turn.”*¹¹⁵
- b. An anonymous witness: *“Further to the release of the 2nd set of Regulations issued by the Government/IBCA, the infected community are extremely concerned and despondent regarding the amendment to the Severe Health Conditions (Special Category Mechanism SCM) criteria, which has a devastating effect on the level of compensation victims are being offered ... The 2nd set of Regulations seek to remove the aforementioned criteria of those who would automatically qualify due to their enhanced status under the Support Schemes. This cannot be allowed to happen; the impact of this proposed change will be financially devastating.”*¹¹⁶
- c. Gene Matthews of Leigh Day: *“From my reading, the uplift under the Supplementary Route Regulations is only awarded in respect of certain severe health conditions and while some are recognised extra-hepatic manifestations, individuals have the additional burden of needing to evidence certain treatment has been obtained as a result of their extra-hepatic manifestations in order to be eligible. In relation to the uplifted financial loss and/or care awards for individuals diagnosed with a severe psychiatric condition(s), including bipolar disorders, depressive disorders and/or post-traumatic stress disorders, not only will individuals need to evidence this diagnosis and that it was caused, or majorly caused by, their underlying HIV/HCV/HBV diagnosis, they will also need to evidence the fact they have received, at least, 6 months of consultant led treatment or have been involuntarily or voluntarily sectioned. In respect of the care award, individuals need to be able to evidence a social services needs assessment has taken place which confirms their care requirements meets the description of the 'low care' band, as defined in the*

¹¹⁵ Second Written Statement of an anonymous witness W1150 WITN1150004 §13.

¹¹⁶ Second Written Statement of an anonymous witness W1822 WITN1822004 §7 and §9.

Scheme. The additional, unexpected requirements are in almost all instances unobtainable by individuals.”¹¹⁷

- d. Nicola Leahey: “... we were not consulted in the formulation of a list of illnesses, conditions that we have had to endure over the years and continue to suffer until our deathbed. Why should we have to continue to jump through hoops, relive our stories and the subsequent struggle to gain recognition of our health issues ... The process of compiling the list of illnesses and conditions failed to include input from the victims. This fundamental flaw undermines the list's accuracy and comprehensiveness, as it overlooks crucial experiences and long-term health consequences. This lack of consultation further exacerbates the trauma experienced by us.”¹¹⁸
- e. John Lister: “There was some small consolation when it was stated that those of us receiving Special Category Mechanism would be awarded additional compensation for the hideous, life changing and life limiting conditions caused by the Hepatitis infection/s and/or treatments for these infections. This has now been cruelly snatched away by the government ... Shortly after I was diagnosed with Hepatitis C, I tried to take my own life. I had recently lost my business and my home due to my health problems and inability to work and the diagnosis was just too much to process. I came very close to succeeding ... and was in hospital for 2 months. During this time, I did not have regular consultations with a Consultant Psychiatrist nor was I sectioned. I have hundreds of references in my medical notes to depression and anxiety over decades yet none of this will be taken into account for the purposes of supplementary compensation due to the completely unrealistic regulations.”¹¹⁹
- f. Graham Manning: “This dreadful treatment [interferon] that completely changed my life does not seem to warrant any compensation.”¹²⁰

30. Statements received by the Inquiry also raise concerns around the scheme’s approach to compensating individuals infected with Hepatitis B. These include the exclusion of individuals infected with Hepatitis B from interim compensation or ongoing support payments and a lack of recognition of the particular impacts of Hepatitis B infection.

¹¹⁷ Written Statement of Gene Matthews WITN7762001 §§80-81.

¹¹⁸ Third Written Statement of Nicola Leahey WITN0223015 §§7-8.

¹¹⁹ Second Written Statement of John Lister WITN1350002 §§2 and 7.

¹²⁰ Emailed letter to the Inquiry from Graham Manning. Graham gave evidence on 7 June 2019 INQY1000016.

- a. Paul Desmond, CEO of the Hepatitis B Positive Trust: *“We have a deep concern at the moment, that in attempting to establish a system of rules for compensation, less informed and uneducated individuals have adopted the same parameters for HBV as they have for HCV, when both conditions affect an individual and progress in very different ways, causing very different impacts, both acutely and over time. ... HBV victims feel that they are once again being forgotten and that the focus is, as usual, on those who are already receiving financial support, having been infected with HCV or HIV. The exclusion of victims of HBV from infected blood support schemes is an injustice that is now being perpetuated by IBCA. The failure to prioritise these patients means that many more of them will pass away prior to ever seeing any kind of justice for what happened to them.”*¹²¹
- b. Dr Justine Gordon-Smith: *“We object to the tariff system, which discriminates between viruses. We also object to the lack of regard shown to HBV victims who are not recognised by the support schemes, and are also not being prioritised by IBCA, despite the severe health impact.”*¹²²

The 31 March 2025 cut-off

31. A further concern expressed in statements submitted to the Inquiry concerns the impact of the Government having set a 31 March 2025 deadline for registering with an existing support scheme, with particular concerns relating to the position of bereaved partners and people who remained outside the cut-off dates for the schemes and were therefore not allowed to register. There is also concern about discretionary payments not approved until after 31 March 2025 and child support payments paid after 31 March 2025 being counted towards compensation calculations by IBCA.
 - a. Samantha May of the Hepatitis C Trust: *“Over the past few months it seems to be harder than ever to be accepted onto a support scheme. We have heard from people with really strong cases turned down by EIBSS. And there is now the added pressure of the 31st March deadline. One person was told her appeal has to be in by the 31st March; I do not know where that leaves people who are only beginning the process now.”*¹²³

¹²¹ Fourth Written Statement of Paul Desmond WITN0479044 §§27 and 35.

¹²² Third Written Statement of Justine Gordon-Smith WITN2632085 §48.

¹²³ Third Written Statement of Samantha May WITN0912009 §14.

- b. An anonymous witness from the Tainted Blood Widows Group (commenting on attempts to affect decision-making regarding compensation): *“Some of the issues I have raised are extremely important, for example, only widows registered with IBSS before the 31st March 2025 qualify for the IBSS lifetime support payments. If someone who is infected and terminally ill with very short life expectancy dies before 31st March, their widow has 30 days to register to join IBSS. If that victim were to hang onto life and die a few days after the deadline their widow will not be entitled to the ongoing support payments.”*¹²⁴
- c. Bill Wright: *“Given that I had been receiving SIBSS support payments monthly since 2016, I am anxious to see any offer in terms of any implication for what is a major part of our household income and the provision for my wife should I pass away 31st March 2025. The Government have recently confirmed that the position is that, if an infected person passes away after 31 March 2025, their bereaved partner will not be entitled to support scheme payments. This has caused me and other members of the community great anxiety.”*¹²⁵
- d. Joyce Donnelly and Tommy Leggate on behalf of the Scottish Infected Blood Forum: *“The Government has also recently announced that if an infected person passes away after 31 March 2025, their bereaved partner will not receive support payments. Again, this has caused great upset and anxiety.”*¹²⁶
- e. Carolyn Challis: *“the EIBSS eligibility criteria remain[ed] unchanged, meaning the September 1991 cut off date [was] still being enforced ... I am almost 70 years old, and I have been fighting for inclusion since 2004 when I was rejected by the Skipton Fund because of the timing of my infection.”*¹²⁷

Position of affected children, parents and siblings

32. Particular concerns have been raised, both in the witness statements and in the many communications received by the Inquiry, in relation to the treatment of affected

¹²⁴ Written Statement of an anonymous witness W7756 WITN7756001 §7.

¹²⁵ Fourth Written Statement of William Wright WITN2287087 §15.

¹²⁶ Second Written Statement of the Scottish Infected Blood Forum WITN7165016 §25.

¹²⁷ Third Written Statement of Carolyn Challis WITN0622013 §4.

children, parents and siblings in the compensation scheme, both as to the awards available to these groups and their involvement (or lack of it) in decision-making.

- a. Richard Newton of TB: Affected Siblings & Children: *“One of our main issues is that I do not feel our group has been involved at all in any of the decision making. I thought this would be like a mediation situation, with a two-way conversation when we would be asked for our views and opinions and it would lead to a change in the situation. Instead, it feels like we are being dictated to by one person (the government) who chose what questions to answer and we are only being included to give lip service to stated position that they are consulting the community. ... Even the announcement before Christmas where they changed rules on siblings (meaning I will be paid £34,000 compensation rather than zero) I thought 'Whoop de doo', as it is £2.54/day. Great. That will pay for my milk for the last 37 years of suffering.”*¹²⁸
- b. Denise Turton: *“I have had to fight to be involved since the publication of the report in May 2024. It was not easy. I firstly contacted IBCA explaining that I was willing to help and be involved as I felt that parents that had lost children as children were not being represented by any other group. ... I speak to other parents who have lost their children, but there's not much we can discuss as we have no say in anything at all.”*¹²⁹
- c. Timothy Wratten of the Fatherless Generation: *“I believe people within our group are struggling as the government forgets that we are children who had to watch these things unravel and believe that counselling should be available over the long term for our members and their children. We are also concerned that many of the older adults in our group who watched parents die will die without any recognition. I know that some are suffering with age related complaints and cancer and they should not be kept waiting.”*¹³⁰
- d. Christina Burgess, Director Haemophilia & Bleeding Disorders Counselling Association: *“Two vulnerable groups I am concerned about are the parents of children and also the children of parents who died. Children and elderly parents have already waited far too long for recognition of their experiences.*

¹²⁸ Second Written Statement of Richard Newton WITN6897002 §§11 and 38.

¹²⁹ Third Written Statement of Denise Turton WITN1575049 §§1 and 10.

¹³⁰ Second Written Statement of Timothy Wratten WITN1619006 §§10-11.

*For any parent, the loss of a child is the very worst thing that can happen, yet they seem to have been left at the bottom of the pile, along with the children, and many elderly parents may pass away without ever receiving a full acknowledgement of what they went through ...*¹³¹

- e. An anonymous witness: *“The disparity between the amount paid to siblings and other affected people is so vast that it implies that the sibling’s suffering is less important ... The psychological impact of witnessing your sibling’s illness progress and their suffering develop is simply harrowing. As you can expect and as the Inquiry observed, many affected siblings have suffered (and are suffering) lifelong psychological trauma with many developing long-term mental health issues including PTSD and depression. For many affected siblings, this event unfolded in their formative years which profoundly affected their development and identity. Historically, no psychological support was ever offered to siblings which has compounded the effects of these tragic events ... Many took on significant burdens when giving care to their sibling. The psychological trauma which came from their position meant that many were denied a proper education and for many, their career’s trajectories were ultimately curtailed. The knock-on effect of this has led to lifelong financial and developmental hardship for many siblings.”*¹³²

Anomalies in the Regulations, care awards and financial losses related to infection in childhood

33. Certain issues as to the operation and application of specific regulations have been identified in statements.¹³³

34. Ben Harrison of Milners Law identifies a concern regarding Regulation 7 of the 2025 Regulations, which provides a calculation for establishing an infected person’s past financial losses: *“The existence of the past financial loss calculation is, to my mind, the clear breaking of a promise made to the infected community because the*

¹³¹ Letter from Christina Burgess to Sir Brian Langstaff HBDC0000001 p2.

¹³² Second Written Statement of an anonymous witness W0128 WITN0128003 §§10-12.

¹³³ The issues identified here cannot be easily summarised due to the complexity of the Regulations and are addressed in more detail in the written statements of Ben Harrison and Gene Matthews.

*application of the past financial loss equation results in a deduction from a past financial loss award to a person who chooses to remain registered with IBSS.”*¹³⁴

35. He also identifies concerns regarding the method for establishing the dates when changes in the level of severity of an infection are deemed to occur in the absence of evidence, pursuant to regulation 20(7) of the 2025 Regulations: *“The problem with the drafting is that the Relevant Date is defined as the date at which the Claimant’s application for compensation is made. This produces perverse results. ... I believe that this will likely prove a significant problem for those claimants who were the recipients of whole blood transfusions. I say this because whilst fully acknowledging that those with bleeding disorders frequently have incomplete medical records, there was a tendency amongst haemophilia doctors to monitor their patients’ liver health (whether they told their patients or not) and there further tends to be more by way of medical records for those with bleeding disorders because of different record keeping requirements. ... For any claimant who is unable to adequately evidence the dates at which the severity of their infections changed, I fear that it is an almost certainty that their financial losses will be undercompensated.”*¹³⁵

36. The statement of Gene Matthews of Leigh Day also describes concerns relating to past and future loss calculations and care award deductions. These include:

- a. *“What is not clear is why the past care award is deducted under the IBSS Route only and why the IBCA and/or Cabinet Office have described this deduction as relating to gratuitous care when it is obvious, in some instances, more than 25% is deducted.”*
- b. *“In some instances, the deduction has been described as necessary because past care was cheaper, whether this be professional care paid for privately or gratuitous care calculated using the hourly rates of carers, but this still does not explain why this deduction only applies to the IBSS Route.”*
- c. *“It is apparent that in claims where the individual is placed in a higher severity banding, the care award deduction is significantly higher than 25% and where the individual is placed in the chronic HCV/HBV banding, the financial loss award is calculated to ensure that a percentage of the past and*

¹³⁴ Written Statement of Benjamin Harrison WITN7759001 §98.

¹³⁵ Written Statement of Benjamin Harrison WITN7759001 §§106, 114 and 116.

the entirety of the future financial loss award is deducted; directly contradicting what has been stated by the IBCA and the Cabinet Office. Clarity is necessary on these points to ensure the Community are aware of the reasons behind such deductions and further information is sought to investigate whether these deductions are fair and appropriate.”

- d. *“In addition, the individuals within the Community who are most likely to be affected by this are younger individuals who are placed in the chronic HCV/HBV banding. In these scenarios, both the past care and past financial loss award is subject to significant deductions.”*¹³⁶

37. Dr Justine Gordon-Smith describes a number of issues arising from the scheme’s approach to care awards in her statement, including the following: (describing the Government’s explanation of the rate at which the care award is calculation and the reasons for reducing it by 25% at a meeting on 25 February 2025): *“The explanation lacked any recognition of care or how care services are delivered and assumed that we victims do not understand ourselves. Had commercial care been provided even by the council, the costs would have included, administration, holiday pay, public liability etc and been considerably higher per hour. ... The government insults us when it makes these statements and proposes such a low award for care and diminishes our experience by valuing it as the minimum wage less 25%. I think on a personal level that it offended me so much because it is an insulting award for care providers who have, as we did, endured a living hell. They are also downgrading the value of care as the victims got sicker, arguing that the existence of antivirals was a magic wand, where everyone miraculously was cured, despite years of liver damage.”*¹³⁷

38. The Scottish Infected Blood Forum, Contaminated Blood Campaign and others (in a document entitled “Infected Blood Compensation: Getting It Right”): *“Pre-working Age Discrimination ... even if losses were not related to earning potentiality due to being too young to work, there were still employment related damages/losses involved. Viral impacts would have negatively affected a person’s education, and it is*

¹³⁶ Written Statement of Gene Matthews WITN7762001 §§64, 65, 69 and 70.

¹³⁷ Third Written Statement of Justine Gordon-Smith WITN2632085 §21.

known that compromised academic attainment reduces the opportunities for access to better paid jobs and career progression."¹³⁸

39. Graham Manning told the Inquiry: *"There doesn't seem to be any recognition for infection as a child and the impact this had on schooling and attendance, suffering from brain fog and fatigue and feeling stupid"*.¹³⁹

Unethical research

40. The approach taken to unethical research awards is a further area of concern highlighted in statements received by the Inquiry. A particular issue is the Government's approach to the eligibility criteria for this award.

- a. Luke O'Shea Phillips, who was infected aged three as part of a trial at a centre not listed by the Government as eligible for the additional Autonomy award: *"I do not feel seen in this process. I do not feel that the reality of what was done to me is being properly acknowledged. I was used as a test subject. This is the part that I cannot live with. This is what keeps me up at night. This is what I've had to carry every single day of my life. I did not receive contaminated blood that was meant to save my life. I was not an unfortunate victim of a dangerous treatment. I was a child – a toddler ...*

- *I was not just unlucky. I was chosen.*
- *I was not a recipient of a tragic mistake. I was part of a calculated decision.*
- *I was not just infected. I was experimented on, knowingly, without consent, without protection.*

The evidence is there – in the letters and notes that I hold as a core participant in the Inquiry. I have the proof that I was subjected to something that should never have happened to any human being, let alone a child. And yet, despite this evidence, I am still being treated the same as everyone else ... This is more than painful. It's life-destroying. And it's not justice."¹⁴⁰

¹³⁸ Infected Blood Compensation: Getting It Right WITN7165021 p14.

¹³⁹ Emailed letter to the Inquiry from Graham Manning. Graham gave evidence on 7 June 2019 INQY1000016.

¹⁴⁰ Email from Luke O'Shea Phillips received by the Inquiry. Luke gave evidence on 4 June 2019 INQY100013.

- b. Stuart McLean: *"I was unhappy with the decision to award fixed sums of £15,000 to the former pupils of Treloars, along with the £10,000 being awarded to people who received "treatment" at a limited number of hospitals during a certain time period. This I believe is too restrictive and does not recognise the extensive amounts of research that was carried out on Haemophiliacs and people misdiagnosed with haemophilia across the country. There should be a way outside of the fixed parameters of this award, for individuals to prove that they were the subject of unethical research."*¹⁴¹
- c. Nigel Hamilton of Haemophilia Northern Ireland: *"Members and I are very upset at the news that Belfast is not considered to have been one of the centres carrying out unethical research. I find this astonishing. It is well established that Dr Mayne was, along with Professor Bloom in Wales, one of the leading clinicians at the relevant time and that Dr Mayne acted with little if any sense of accountability. I personally know that she was taking blood for liver tests when we were teenagers. She was clearly carrying out some sort of research. The Government seem to suggest it is incumbent on us to prove otherwise. How can we do that? This has angered people in Northern Ireland, who see this as another example of the English centric nature of the whole process."*¹⁴²

Impact on campaigning and support groups

41. The Inquiry has received a significant body of evidence from groups supporting the infected blood community which describes – often in stark terms – the strain that they have been under since the Government’s announcement of the compensation scheme.
 - a. Samantha May of the Hepatitis C Trust: *"We had to employ an additional person to assist on the helpline a few months ago, but this is still nowhere near enough. Organisationally, we are overwhelmed. We do not have the resources to manage the number of requests for help we are receiving about the compensation scheme since the publication of the Inquiry's final report and the regulations. The emotional toll on staff and volunteers is massive. We so desperately want to help people as we have always done over the last 21 years, but we simply do not have the capacity and they have nowhere else to*

¹⁴¹Second Written Statement of Stuart McLean WITN0653028 §18.

¹⁴² Second Written Statement of Nigel Hamilton WITN2340014 §57.

*go for the kind of support and guidance we provide. ... For me and the other members of staff and volunteers at the Hepatitis C Trust who have been working on this, the impact has been indescribable. It has been completely overwhelming. Personally speaking, and despite managing the helpline for 21 years and being acclimatised to hearing extremely difficult stories, it has been very destabilising.”*¹⁴³

- b. Lynne Kelly of Haemophilia Wales: *“Haemophilia Wales is entirely funded by donations and represents over 300 infected and affected Haemophilia and transfusion patients, families and bereaved families. We are unpaid volunteers with no staff, and I run the charity on my own with the support of the trustees. ... I would challenge anyone to deny that the daily work load of Haemophilia Wales is not debilitatingly stressful, personally, and to the members who have already been so damaged by 40 years of the same shameful behaviour by successive Governments.”*¹⁴⁴
- c. Nigel Hamilton of Haemophilia Northern Ireland: *“I am a volunteer for my Society and the infected community. I estimate I am spending more than 20 hours per week directly engaging with members of the community in both Northern Ireland and the UK mainland, addressing victims' concerns, answering questions, helping reassure and guide victims queries, attending face to face and virtual meetings and doing research and clarification of suggested policy. The tasks and enormity of the responsibilities, if one is diligent, are considerable, and apart from pressure both in stress and time the financial burden is not light. ...”*¹⁴⁵
- d. Kate Burt of the Haemophilia Society: *“The Society lives by its values of compassion, empowerment and resilience. Since 20 May 2024 I have witnessed our trustees and staff team demonstrate all these to an incredible level to support our community. But we have been tested to our limits as individuals and as an organisation. As Chief Executive, it is very difficult to see the impact this has had on my colleagues, both staff and trustees. ... We will obviously do everything we can to support those infected and affected in the community we have represented for 75 years this year. However, the*

¹⁴³ Third Written Statement of Samantha May WITN0912009 §§28, 29 and 70.

¹⁴⁴ Second Written Statement of Lynne Kelly WITN3988094 §§73 and 75.

¹⁴⁵ Second Written Statement of Nigel Hamilton WITN2340014 §§36-37.

*Society is now on its knees in many ways. The staff and trustees are exhausted as a result of the relentless queries and support required; however, alongside the concern for the infected and affected community is the concern for the future of the Society. The Society is in the worst financial position it has ever been in.*¹⁴⁶

Psychological support

42. The ongoing lack of psychological support in England remains a central concern for witnesses.

- a. Kate Burt of the Haemophilia Society: *“The Society has been lobbying for specialist psychological support for the UK's infected and affected community since it wrote to then Prime Minister, Theresa May, in September 2018 and the Cabinet Officer Minister, David Lidington in January 2019 (see Exhibit WITN6392295) amongst others. The Society also highlighted its concerns by initiating media coverage on Channel 5 News on 24 February 2020, to coincide with the issue being discussed at the Infected Blood Inquiry. Happily, services in Wales, Northern Ireland and Scotland have improved dramatically since then, but the same cannot be said for England. We were informed by the Paymaster General in August 2024 that the Infected Blood Psychological Service was to be ready to support its first patients in England later in the summer of 2024 ... As I write this, the Infected Blood Psychological Service is still not fully set up with only a few psychologists in place and the national structure and referral system still not operating. This lack of external support has put considerable additional pressure on the Society. The infected and affected are clearly struggling and have nowhere to turn for support therefore they call the Society. The Society staff are providing emotional support as well as what guidance we can on complex financial and, in the case of probate issues, legal matters. Some callers are extremely isolated and have not confided in friends or even family about their link to the contaminated blood scandal. They know their call will always be welcome at the Society, but there is a limit to the support and information we can offer them.”*¹⁴⁷

¹⁴⁶ Fifth Written Statement of Katherine Burt WITN6392288 §§38 and 58.

¹⁴⁷ Fifth Written Statement of Katherine Burt WITN6392288 §§19-20.

- b. Denise Turton: *"In addition to the above, there is still no psychological support for any of us. It was in the interim recommendations but it is still not being implemented. A lot of people need support. There are a lot of parents who are now elderly, and it is not easy for them. They have age-related illnesses such as cancer and dementia and also tech related limitations. We have fought for decades and many, many parents have died and it still feels like we are totally ignored. To me feels like ongoing mental torture and I am finding it very hard."*¹⁴⁸

Estate claims

43. A number of statements describe problems relating to interim payments to the estates of the deceased, with particular issues in cases where the estate executor had died. While steps were taken by IBCA and the Cabinet Office to address these issues, witnesses describe the negative impact of delays in payments, communication issues and uncertainty on the community.

- a. Nigel Hamilton of Haemophilia Northern Ireland: *"The debacle of the Chain Estates is one very good example in point. These are the estates of deceased victims, where the executors themselves have passed away. Therefore, one has to go down the 'chain' to the next level of people who can act for the estate. The £100k payments to estates who had received no money for the loss of their loved ones became a very disconcerting process. I know of 5 cases in Northern Ireland. The very first case in the UK was case number 0001 and after receiving an email confirmation that the family would receive the compensation with a request for banking details the following day, they received an email advising them that the process had been abruptly stopped for them, as there were Cabinet Office concerns, that HMRC required additional, at that time not defined, evidence that the family was entitled. We brought this matter to the Cabinet Office and following pressure from the lobby, a simple process of approval was inserted and once qualification was confirmed, the process of approval would go forward, yet no monies have been forthcoming."*¹⁴⁹

¹⁴⁸ Third Written Statement of Denise Turton WITN1575049 §14.

¹⁴⁹ Second Written Statement of Nigel Hamilton WITN2340014 §45.

- b. Gene Matthews of Leigh Day: *“At the time [of an 11 October 2024 letter], I was also contacted by several of my clients who had been provided incorrect information regarding what document was necessary in respect of their loved one's estate. ... In response to this correspondence, the IBCA sent an update to the Community dated 24 October 2024 [WITN7762013] which provided a link to the guidance available on the Government website regarding applications for Grant of Representation [WITN7762014]. ... I also understand that instructions were provided to the Probate Registry in relation to applications linked to the Scheme and several of their employees were dedicated to processing these applications and a designated email address was set up to respond to queries and concerns by the Community. In instances such as these it is apparent that IBCA can take steps to resolve live and urgent problems but as ever, the communication provided to the Community is not always clear. The guidance did not provide clarity regarding the chain of representation point, as set out above and while it is has since been updated, setting out that this is possible in claims where a will was in place and individuals obtained Grant of Probate, it does not however, explicitly confirm this is not possible in relation to individuals who have Letters of Administration only. I know this as the same client, discussed above, is still being informed that he only needs to obtain Letters of Administration in respect of his mother's estate to process his father's Scheme application.”*¹⁵⁰
- c. Danielle Holliday of Collins Solicitors: *“We have assisted around 45 people with their applications for probate and an interim payment. Initially there was a lot of confusion generally following the announcement in October 2024 that IBIEPS was open to receive applications for interim payments to estates. The position regarding what the legal fees would and would not cover was inconsistent. ... On two occasions, we have had applications be approved, a date provided for when we can expect the money to be received in relation to that client, and then the application has been paused as an additional document is required. Informing our clients that their application has been approved, and even the date the money will be expected, to then tell them their*

¹⁵⁰ Written Statement of Gene Matthews WITN7762001 §§60-61.

application has been paused and they will have to wait longer is very difficult.”¹⁵¹

Proposed changes to the scheme

44. It will be apparent from the extracts from statements referred to in this presentation that significant changes to the design of the compensation scheme and/or to the way it is operated have been proposed by people infected and affected and RLRs. The scope of this presentation does not extend to summarising or identifying these. They will no doubt be the subject of written submissions following the 7-8 May 2025 hearings.

JENNI RICHARDS KC

ADAM BOUKRAA

Counsel to the Inquiry

29 April 2025

¹⁵¹ Written Statement of Danielle Holliday WITN7763001 §§134 and 150.

APPENDIX: STATEMENTS REFERRED TO IN THIS PRESENTATION

1. Alan Burgess and an anonymous witness on behalf of the Birchgrove Group WITN7752001
2. An anonymous witness WITN0128003
3. An anonymous witness WITN1150004
4. An anonymous witness from The Forgotten Few WITN1791047
5. An anonymous witness from the Tainted Blood Widows Group WITN7756001 and WITN7756002
6. An anonymous witness who supports infected and affected people WITN7758001
7. An anonymous witness WITN1822004
8. Andrew Evans, Tainted Blood WITN1213015
9. Benjamin Harrison, Milners Solicitors WITN7759001
10. Bruce Norval WITN2235014
11. Carol Grayson, Haemophilia Action UK WITN1055207
12. Carolyn Challis WITN0622013
13. Clair Walton WITN1589029
14. Colin Midgeley WITN3968002
15. Cyrlia Knight, Saunders Law WITN7767001
16. Danielle Holliday, Collins Solicitors WITN7763001
17. Danielle Mullan WITN2439002
18. David Leadbetter WITN7765001
19. Denise Turton WITN1575049
20. Gary Webster (on his own behalf and on behalf of other Treloar's pupils: Steve Nicholls, Richard Warwick and Adrian Goodyear) WITN1723044
21. Gene Matthews, Leigh Day WITN7762001
22. Glenn Wilkinson, Contaminated Blood Campaign WITN2050115
23. John Dearden, Haemophilia Scotland WITN7754001
24. John Lister WITN1350002
25. Joyce Donnelly and Tommy Leggate, Scottish Infected Blood Forum WITN7165016
26. Dr Justine Gordon-Smith WITN2632085
27. Kate Burt, Haemophilia Society WITN6392288
28. Lynne Kelly, Haemophilia Wales WITN3988094
29. Mary Grindley WITN2336029
30. Michael Imperato, Watkins & Gunn Solicitors WITN7761001
31. Nicola Leahey WITN0223015
32. Nigel Hamilton, Haemophilia Northern Ireland WITN2340014
33. Owen McLaughlin, TB Affected Siblings & Children WITN7766001
34. Patrick McGuire, Thompsons Solicitors Scotland WITN7760001
35. Paul Desmond, Hepatitis B Positive Trust WITN0479044
36. Richard Newton, TB Affected Siblings and Children WITN6897002
37. Samantha May, Hepatitis C Trust WITN0912009
38. Sean Cavens WITN146047
39. Stuart McLean WITN0653028
40. Timothy Wratten, The Fatherless Generation WITN1619006
41. William Wright WITN2287087