Government Statements

Nick Thomas-Symonds, Paymaster General and Minister for the Cabinet Office [LINK]

Paragraph 47

Inevitably, I have had to strike a balance between speed of delivery and extensive engagement on the Scheme design. I have endeavoured to strike this balance and always put these two factors at the heart of our ways of working.

James Quinault, Director General in the Cabinet Office [LINK]

Paragraphs 51-52

Ministers**:**

- It is the role of Ministers to make decisions on the design of the Scheme, and to put these to Parliament to be voted into law; and
- Ministers remain accountable to Parliament for the overall progress of the Scheme.

Civil servants:

- It is the role of civil servants in the Cabinet Office to advise Ministers on the design of the Scheme and to prepare the regulations to enact this design; and
- The Cabinet Office Permanent Secretary remains the Principal Accounting Officer for IBCA, accountable to Parliament for the issue of grant-in-aid to IBCA.

IBCA

- It is for IBCA to implement the Scheme, deciding for itself how best to do so, consulting the Cabinet Office only where a decision would engage Ministers' accountability to Parliament for the overall progress of the Scheme, or the responsibilities of the Cabinet Office's Permanent Secretary to Parliament as Principal Accounting Officer; and
- It is for IBCA to make decisions on claims, determining and making payments to eligible people as set out by the regulations. Ministers and civil servants working in the Cabinet Office have no say in the decisions IBCA makes on individual claims.

Paragraphs 58-60

IBCA has been set up by the Victims and Prisoners Act 2024 to have the operational freedom to make the necessary decisions to deliver compensation in line with the Infected Blood Compensation Scheme Regulations 2024 and any further regulations related to the Infected Blood Compensation Scheme.

It is for IBCA to make decisions on claims, determining and making payments to eligible people as set out by the regulations.

Ministers or civil servants in the Cabinet Office have no say in the decisions IBCA makes on claims or in any reviews of decisions on claims.

David Foley, interim Chief Executive of IBCA [LINK]

Paragraph 19

In broad terms this means that the Cabinet Office is responsible for setting the policy framework of this legislation which IBCA is then responsible for administering with full operational independence and accountability.

Paragraph 52
We are also working within timescales as agreed with the Cabinet Office which are to pay the first infected person by the end of 2024, to pay the first affected person by the end of 2025, to pay the bulk of infected persons by the end of 2027 and to pay the bulk of affected persons by the end of 2029.

Campaigner Statements

Samantha May, Hepatitis C Trust [LINK]

Paragraph 18
We are dealing with a huge influx of people who have never been tested for HCV despite having had one or more multiple transfusions pre 1996, in some cases going back to the 1960s. We are supporting them to access testing, and treatment if actually diagnosed, as well as having to explain the enormity of their diagnosis in relation to access to the IBSS's and compensation, the history of infected blood and the work of the Infected Blood Inquiry – all of which leaves people in complete disbelief and overwhelmed – on top of the fact they have just been diagnosed with a serious and life-threatening illness.

Paragraph 19
Since the publication of the Inquiry's report in May 2004, we have seen much complex information and regulations pumped out from the CO. Under the new scheme it is clear that individuals with Hepatitis C will have to evidence each part of their treatment and care which means the evidence that has to be provided goes over and above that evidence that was required in relation to the IBSS schemes and very likely the special category mechanism (SCM) although we don't have that information yet. Individuals will have to provide evidence of every stage of their hepatitis along with details of all health conditions and dates.

Paragraph 24
Since the publication of the Inquiry's final report and the information and regulations in relation to the IBCA and compensation scheme the impact on individuals has been huge, both on staff and volunteers at the Hep C Trust and for infected and affected individuals. We have been dealing with newly diagnosed individuals and the existing infected blood community. I can confirm that the distress and confusion of both those 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.

Paragraph 25
Individuals are seeking our help continually, and we are doing our best to try to explain the situation to them, and in some cases, literally hand hold people, step by step. However, we do not have the infrastructure to enable us to do this efficiently and quickly. We do not have the funding to employ more staff, which would be a lifeline, to work on the helpline to enable us to respond to people much more quickly.

Paragraph 60
In a nutshell, as a direct result of the government and CO failures, we, as an organisation:

- are overrun as a service
- do not have time to support people properly
- because we are so stretched, and because so much complex information is being released, we do not have time to fully engage with the compensation process, and therefore cannot provide sufficient information to, or provide sufficient representation for, the community. We find it impossible to digest and process the information coming out of Government and get to a point where we can translate this to the community in good time – this is really problematic for staff and for callers
- have had to bring in people from other parts of the organisation who have limited specialist infected blood knowledge
- find it massively draining and debilitating for our team – everyone is completely exhausted, and the team has done hours of overtime - have incurred additional costs – cover staff, new staff, additional clinical supervision, volunteer expenses

Paragraph 62
The impact of the volume of calls and emails on the Hepatitis C Trust Information and Support Service has been relentless and overwhelming, since the launch of the Inquiry report in May. Following the announcement of the compensation scheme last Summer, enquiries more than doubled from the previous year; 8700 in total in 2024, 7099 of which were in the period May – to December 2024. In addition, in January 2025 we took 752 calls and emails.

Paragraph 77
The impact on the community has been absolutely devastating. It has caused upset, confusion, anxiety, fear, desperation and division unlike anything we have experienced so far in the 21 years of supporting them.

Paragraph 94
We make a desperate plea to the government/CO and IBCA to resolve this situation so that individuals can obtain the compensation they should have received so long ago. We urge the government to take action now to stop compounding the hurt, anguish, distress and hardship that have faced this community for decades.

Kate Burt, the Haemophilia Society [LINK]

Paragraph 4
Given the proximity of the announcement of the compensation scheme to the publication of the Inquiry's final report the Society did not (nor did the wider infected and affected community) have the opportunity to fully digest the Inquiry's findings before having to deal with the immeasurable amount of additional work created by what felt like a rushed announcement by the Government in respect of compensation. On 7 May 2024, the Society met with the then Paymaster General, John Glen MP, where Clive Smith and I suggested that the government should not make an announcement in respect of compensation until the community had had the opportunity to digest the Inquiry report as we did not want any compensation announcement to overshadow the report's findings. Unfortunately, this concern was ignored.

Paragraph 5

Since the announcement, the Society simply has not stopped; if anything the Society has been under more pressure than at any point since the Infected Blood Inquiry was announced in 2017. By way of illustration, in May 2020 the Society received 134 calls, in May 2022 it received 186 calls in May 2024 it received 641. During the third week of May 2024 alone, the Society received 448 calls. The e-mail traffic has also increased significantly, but we do not have the analysis available to evidence the true volumes at this stage. This is not sustainable for such a small charity.

Paragraph 13
In addition to the work of the Society as a whole, individual trustees and staff members are being contacted directly by concerned members of the infected and affected community. One individual described the pressure as “intolerable” and considered closing their social media accounts as a result of the relentless messages seeking support and reassurance. This is a burden which should not fall on the shoulders of individuals, however, this is an inevitable consequence of the lack of centralised support for applicants– see further below.

Paragraph 21
Financially, the Society has received no support whatsoever. With our main fundraiser, Debra Morgan, largely diverted onto compensation-related duties, it has been extremely challenging to raise the funds needed to maintain the charity’s core services. We are operating in a very difficult financial landscape, with ever decreasing funding sources. To ensure we are still here to support the next generation of people with a bleeding disorder as well as meet the demands of our members today, we urgently need the assistance of government funding.

Paragraph 23
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.

Paragraph 27
The meeting with the Paymaster General on 11 December 2024 was highly choreographed, which felt more like an obligation to engage rather than actively listening to the needs of the community. The meeting did not offer the chance of meaningful engagement, which the Society had requested. Being given four minutes to summarise the positions is not enough time to adequately reflect the range of needs and concerns voiced to us by our members.

Paragraphs 28-30
The Society’s principal concern is that the infected and affected were not involved in any of the decision-making regarding compensation until the majority of the key decisions had already been taken. There were some engagement meetings held with Sir Robert in June 2024, but this was long after a significant number of key decisions had already been made. Many of the community feel the lack of transparency and lack of community engagement of the expert group prior to Sir Robert’s engagement sessions has caused many of the ongoing issues.

Many decisions about the compensation scheme were shaped by the government's Infected Blood Inquiry Response Expert Panel which did not consult with the infected blood community at all in making its recommendations.

The most important decisions on compensation relate to the core route tariffs and to the eligibility for those tariffs. These decisions were taken by the Cabinet Office alone based on the advice of the expert group. Despite repeated approaches by the Society and by MPs on behalf of the Society, we have been repeatedly told that they will not revisit those decisions.

Paragraph 32
the Society has been contacted by an individual who was told that her claim was successful on 13 January 2025 and was asked to provide her bank details, which she did. Then on 22 January 2025 she was told that her claim would not be processed on the basis that she had only demonstrated a 'line' of succession and not a 'chain'. There was no explanation within the correspondence as to what this meant or what she needed to do to enable her to submit a successful claim. The Society made contact with the Cabinet Office who subsequently looked into the matter and provided some further guidance on 30 January 2025.

Paragraph 54
When laying the relevant regulations before parliament, it appears that certain incorrect decisions had already been made and, as a result of the wording of the regulations, these incorrect decisions cannot be overturned. For example, the Cabinet Office published a Draft Infected Blood Compensation Scheme Regulations 2025 Factsheet in January 2025. This factsheet states "Because of the way the Victims and Prisoners Act 2024 works, the Scheme has to be set out in law. This law has to provide IBCA with all of the precise detail it needs to assess claims and make payments to everyone eligible for compensation. This is why these new laws will be longer and more complex than the first laws". The Society is concerned that by putting all of the precise details in legislation this in fact ties the hands of IBCA to the extent that it becomes an implementation body and not a wholly independent entity, see Exhibit WITN6392300.

Paragraph 57
The overriding message we are hearing from our members and the community is that the culture needs to change. Sir Brian was clear in his final report that the government has to accept responsibility and there was a strong message that future governments needed to learn from the mistakes of the past and act with a strong sense of candour. Sadly, things have not changed. This government needs to make strides to change the culture and attitude towards the community and ensure that there is meaningful engagement.

Paragraph 58
As a direct result of the energy needed to support the compensation scheme in the ways described above, the Society's staff have been unable to focus on their day jobs and matters such as fundraising have had to take a back seat. Consequently, events have been cancelled (for example Youth Camp which has run in some form since the 1980s). As at the date of this statement, the Society has approximately six months of working capital available to it. Unless something drastically changes in the next couple of months, the Society is at serious risk of not being able to celebrate its 76th anniversary in 2026.

Bill Wright, former Chair/Co-chair of Haemophilia Scotland [LINK]

Paragraphs 12-15

I was invited to join the small list of claimants under the core route pilot. I agreed to this on the basis that it would afford me the opportunity to view the claims process in practice and comment upon it. I had my first meeting with my allotted claims manager on Nov 6th and a transcript was subsequently provided. For part of the meeting, a representative of Public Digital was present. I was happy with this as it offered the learning from the process that was my intention.

The second meeting took place on Nov 14th for which a transcript was also produced. One challenge immediately presenting itself was the need to provide supporting documentation, so I had asked that my wife join the meetings as my partner/advocate. This was in line with another suggestion I had previously made to Public Digital. However, given the importance of producing the correct evidence I also wished Thompsons as my solicitors to take part. This was agreed to. I had also previously emphasised to Public Digital the need for claimants to be able to have present legal professionals as their advocate present. One immediate observation I made was that the evidence required to back core route claims might not be readily available to claimants. I was fortunate in that my wife was able to lay hands on the necessary evidence (6 different documents) most of which I had already provided as supporting evidence with my written statements to the Inquiry. While I was lucky my wife laid her hands upon the required documentation, I suggested that others may have very real difficulty in this respect, and would need assistance from their legal representatives. Such evidence may be in the hands of legal representatives, particularly where statements have been made to the Inquiry.

I was also concerned that IBCA confirmed I would still be able to make a claim under the supplementary route which they confirmed would be the case.

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.

Paragraph 22-25

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.

Secondly, the election announcement meant that the passing of the Victims and Prisoners Bill was unduly rushed in the ‘wash-up’ to get legislation passed. That meant, under Sections 49 and 50, that details of the scheme would be fixed under secondary legislation which had to be drawn up during election purdah and the Parliamentary summer recess.

Neither leg of these foundations had been adequately consulted upon.

A new unknown Minister came into place to oversee this and lead the response, recalling not only the evidence to the Inquiry by the aforementioned Expert Group about Ministerial changes but also changes in Government, particularly from different political parties. It is difficult in particular to avoid linking this to the evidence given to the Inquiry by Andy Burnham and Jeremy Hunt of their experience as Ministers in their dealings with civil servants, particularly where those same officials were answering letters from survivors on their behalf.

Paragraph 28
Indeed, it is difficult to see how the approach taken by Government passes even the most basic of tests on what is good practice on consultation. Failure by Government and the Montgomery group to consult effectively has built in a process of inflexibility. That inflexibility, in turn, makes further consultation and engagement meaningless.

Paragraph 30-31
My own continued involvement in these matters is set against a background of a significant change during 2024 in my own health and personal position. I was diagnosed with Hepatocellular Carcinoma (HCC), namely liver cancer in March 2024, due to the appearance of a 3.9cm tumour in an MRI scan. While querying how such a lesion had grown so large so quickly, I embarked in April on an assessment to join the liver transplant list and underwent my first TACE to reduce the tumour. Having joined the transplant list I was unable to attend the delivery of the Final report in London on May 20th as I was confined to being readily available for a possible liver transplant in Edinburgh should I be called at any time when a suitable donor liver became available.

I was subsequently diagnosed in July with a second tumour and ‘downstaged’ off the transplant list. This was a highly dispiriting turn of events, implying a much-shortened potential lifespan. My attention turned to ensuring that my wife would continue to receive ongoing SIBSS payments after my passing. Scottish Government had repeatedly assured us that these would last for life. I feared that under the proposals set out by the UK Government, my wife would not be allowed the choice of whether to continue monthly SIBSS. As mentioned above at paragraph 15, the Government has now confirmed that, if an infected person passes away after 31st March 2025, their bereaved partner will not receive support payments.

Andrew Evans, Tainted Blood [LINK]

Paragraph 2
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 or no input from the infected blood community. Therefore our efforts have been in part focused on protest against this fact, and in part attempting to work with the existing compensation scheme setup to improve whatever we could.

Paragraph 3

We very quickly learned that the Expert Group advising the Cabinet Office, headed by Jonathan Montgomery and (as was then) a team of experts whose identities were undisclosed, had not been privy to the testimonies of victims at the Infected Blood Inquiry, nor had they sought to gather information or evidence from them. That these decisions were, in fact, based solely upon the knowledge and opinion of these secret experts, from the perspective of the general population and historic tropes of medical and scientific understanding, without the context of the actual scandal to advise them.

Paragraph 7

By not engaging with the community or with the breadth of knowledge gained by the Inquiry, we argue that the government has not met its duty to engage at the crucial time that decisions about the compensation scheme were made. This is the seed that has resulted in a compensation scheme that is not fit for purpose.

Paragraph 9

We are, and always have been, volunteers and victims of the scandal, and seek to do the work necessary to achieve as much of a sense of justice for our fellow sufferers as possible. We had thought, following the Inquiry's reports, that our task to do so was to be made easier, however this has not been the case and, in fact, the onus upon us to understand and challenge the scheme has forced our time input to be greatly exacerbated. Indeed, many members of the Tainted Blood Steering Committee have faced burn-out and have had to withdraw in order to protect their mental health.

Paragraph 13

In short, our involvement from the perspective of achieving meaningful effect upon decision-making has been negligible. I set out the reason for this in my answer to Question 1, but to recap: the majority of decisions around compensation had already been made, it seems unalterably, before we even had a chance to engage. Engagements past this point have been tokenistic and, at best, tinkering around the edges of a ready-made scheme that appears to all intents and purposes to be set in stone.

Paragraph 15

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, with some members actively withdrawing in order to protect their already fragile mental and physical health, leaving fewer of us to pick up their work. In attempting to engage with both IBCA and the Cabinet Office, we have been forced to, once again, relive the trauma of the past in order to evidence our reasons that the compensation scheme is in many aspects not fit for purpose. To have these efforts apparently fall on deaf ears has led to a sense of complete frustration, desperation and hopelessness. In many cases this has resulted in further exacerbation of physical illness as well as the obvious mental impact.

Paragraph 21

since the Inquiry's final report we have been left without any form of legal assistance to advise us on the steps available to us to take in order to attempt to achieve our goals.

Without this vital support it has been left to us to attempt to interpret complicated regulations and discover issues with them, without the proper training to do so, and to attempt to challenge these issues alone. We are volunteers, we cannot afford legal support ourselves, and so we go without. To have something in place to alleviate this would be of immense help.

Paragraph 22
We do what we do because it is the right thing to do. All we seek from here is an easier path upon which to do it.

Gary Webster, Treloars Group [LINK]

Paragraph 7
as a group we feel saddened and frustrated at the slow pace of Government action and lack of urgency, this only compounds our feelings of mistrust towards the political system and somewhat undermines the Inquiry's report and recommendations.

Paragraph 19
We do not understand why our solicitors cannot just prepare the paperwork and submit it with all the relevant evidence to allow the correct calculation to be made through the core route.

Paragraph 21
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. I don't know if it is the Cabinet Office holding back IBCA, if it is we would rather they just be honest and say so.

Paragraph 28
There is a growing realisation among victims that at the current rate of 'progress' very few of us are likely to see justice served in a timely manner, or even in our lifetime!

Lynne Kelly, Haemophilia Wales [LINK]

Paragraph 15
We remain concerned that Alder Hey Hospital is excluded and asked for clarity that patients from Carmarthen, Swansea and Newport Haemophilia Centres will also be included in the unethical research award as Prof Bloom purchased all blood products via Cardiff Haemophilia Centre and those products were then distributed to the smaller centres across Wales.

Paragraph 31
This is not what was envisaged. What was envisaged and expected after 7 years of the UK's largest Public Inquiry, was that there would be a general acceptance of the Inquiry's recommendations, as the Inquiry had already engaged extensively with infected and affected and all evidence had been published. What was **not** expected, was the protracted negotiation by stealth with the Government that we are engaged upon.

Paragraph 45
The IBCA default position on all the key matters is ‘we are awaiting direction from the Cabinet Office’. The responses from The Cabinet Office are similarly vague on points of principle which instead of being openly discussed in meetings are ‘floated’ out in communications as if they have been debated and thoroughly discussed and agreed with the community. Which they have not.

Paragraph 51
The community still do not know how and when they are to properly register their claim 19 months after Sir Brian’s 2nd interim report on compensation.

Paragraph 59
A major concern is the way access to legal advice is so limited. At present, any help we are given is generally through the good grace of our lawyers doing it for free. There seems to be a distrust of our lawyers, lawyers who have acted for us and the community, through thick and thin, for nearly ten years now. At the recent meeting with James Quinault, he said the Government were procuring other law firms services as well as recognised legal representatives if they wanted to be involved. I said that this was not acceptable as our members trusted our legal representatives and would not want to be advised by new lawyers they did not know and trust. I felt this approach undermined the importance of our long established recognised legal representatives. I was also astonished when I heard that the Government/IBCA were seeking at one point to gag our lawyers, not allowing them to speak to us about any concerns they – the lawyers – had with the scheme.

Paragraph 80
Worryingly as the recommendations of Sir Brian’s Report have not been taken up by The Cabinet Office, a distance grows from its publication. With new administrators starting to populate the Cabinet Office/IBCA and as the case worker army grows, ‘the new line to take’ seems to be taken from Jonathan Montgomery’s report. The Inquiry findings are in the back office somewhere, but as the findings have not been implemented, the report and the evidence of 4000 people is set aside and devalued, and so the mistakes that were so difficult to record that it took 7 years to write them down are being remade by a new generation of administrators.

Paragraph 81
It feels that some of the fundamental failings of the State – and in particular the Civil Service and Politicians - are being revisited on us all over again. Sir Brian Langstaff was very critical in the Inquiry report of the Civil Service taking a line early on which they would not move from. That is exactly what has happened here, with the compensation scheme and apparatus being designed in secret with no input from victims and now, as its failings are exposed, a refusal to move or to take on board suggestions for change.

Nigel Hamilton, Haemophilia Northern Ireland [LINK]

Paragraph 25
There was a meeting with Nick Thomas Symonds (NTS) on the 11th of December 2024, 5 months following his appointment. Also present were Cabinet Office civil servants. It was a

meeting of victim representatives from the devolved regions. We were allocated 4 minutes to speak. I found this took the shape of a Funeral Director's handshake. The Minister appeared to be less committed, answering questions in brevity and conscious that he had over 16 groups to 'get through'. It felt for all of us, that it was an exercise to tick the box that he would report back to the Parliament before the recess.

Paragraph 28
My direct dealings with the Cabinet staff have allowed me to speak on issues of concern. It seems clear to me that IBCA, as an organisation, is umbilically attached to the Cabinet Office. On several occasions since my engagement with them, I repeatedly get told that the answer lies with the other while the policy-making Cabinet officials state that they are willing to listen, but it is a one-way traffic process.

Paragraph 36
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.

Paragraph 42
There is a very high level of dismay at the length of time it is taking to process applications, which appear to be picked at random, and the achievement rate has been extremely low and threatens to take years not months as initially suggested. The small number of Case Worker cases was 11 with a figure of £13m compensated. With over 4500 cases infected the time progressing cases is far too slow. I have already lost one victim in Northern Ireland to cancer of the liver on the very day he was advised his case was being put forward for compensation case officer consideration.

Paragraph 43
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.

Paragraph 45
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.

Paragraph 46
It is a great concern and a regret that the Government and Civil Service thought it best to devise the compensation system and the processes IBCA have adopted in secret. In his interim report on compensation from April 2023, Sir Brian Langstaff expressly recommended that victims and their legal representatives should be co-designing with the Government at the outset. Instead, the Government and the civil servants advising them, set up a secret committee to devise everything. By the time the Inquiry had reported, everything was already set in stone. Lines have been taken and set, which the Government and Civil Service refuse to move from.

Paragraph 57
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.

Mary Grindley, independent campaigner [LINK]

Paragraphs 18&19
The day after the compensation framework was announced at the May 2024 hearing, I attended the APPG meeting at Parliament. About 10 minutes into the APPG meeting, we were thinking and talking about how to proceed with the establishment of the compensation scheme. Just then, the general election was announced. We tried to proceed with the meeting, but an MP came rushing in to announce the election. The meeting couldn’t go much further. We were gathered together with the MPs around somebody’s iPad to hear the announcement from Rishi Sunak that he made in the rain.

At this time Dianna Johnson MP was chairing the meeting and the other MPs at the meeting had to leave to deal with parliamentary affairs. I remember feeling disappointed that after the previous day’s celebrations, we were now struggling once again to have the full attention of those MPs responsible for the implementation of Sir Brian Langstaff’s recommendations.

Paragraph 24
Another issue causing extreme concern and frustration to victims is the exclusion of our recognised legal representatives from the establishment of the framework for the Infected Blood Compensation Authority. It was Sir Brian’s intention and recommendation that lawyers representing victims in England, Scotland, Wales and Northern Ireland would form part of the group responsible for the setting up of the compensation scheme. That did not happen and as a result there have been numerous legal problems with the current scheme.

Paragraph 43
I am particularly concerned about the widows who are not represented by any group and who are confused with the situation, some of whom are in financial difficulties.

Paragraph 56
When we had the closing event in May last year and the compensation was announced, the community was elated. When Sir Brian announced after 5½ years of hard work by himself and his team, and years of the community's campaigning, that infected blood was no accident, we felt we were finally listened to and our story had been told. We felt vindicated and someway to partial closure, but now, with the lack of engagement and lack of progress, once again the community is on its knees.

Paragraph 57
The mood is now one of anger, frustration, despair, stress, and disbelief again. We have been made to feel like second class citizens once again.

Stuart McLean [LINK]

Paragraph 18
They need to consider the serious health consequences to our community. If you were to catch HCV today, you would be treated with safe and effective drugs and likely cured within 6 months. However, 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. This has not been considered. 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.

The Birchgrove Group [LINK]

Paragraph 8 (c)
The people with whom the Cabinet Office and Infected Blood Compensation Authority ("IBCA") have sought to engage are the leaders of the campaign organisations which the Infected Blood Inquiry is familiar with. Many of these people have been involved in campaign work for more than a quarter of a century and had hoped that that work had come to a successful conclusion with the Inquiry's May 2024 Report. Instead, we are now expected to act as a conduit between the Cabinet Office and IBCA on the one hand and the wider infected and affected community on the other. We are expected to do this without any external assistance and in effect, with one arm tied behind our backs; provided with information which is largely unfathomable to a lay person.

Paragraph 25
Another recent topic of consultation has been how awards for unethical research should be applied to claims; the IBCA's initial proposals had limited the fixed sum awards of £15,000 to

former pupils of Treloars and £10,000 to infected people treated at a small number of hospitals between certain date ranges. These proposals are considered inadequate by us and the Birchgrove Group because they fail to recognise (amongst other things) the widespread research which was conducted by Craske and the UKHCDO at Haemophilia Centres throughout the country.

Paragraph 27 (b)
We were then told that it could well take 5 years to pay compensation to everyone which left us terrified; many of the infected and particularly co-infected community simply don't have that amount of time to wait.

Paragraph 40
With the exception of the written submissions which were made in summer 2024, we cannot recall a single instance where the IBCA has changed course because of something said to it by or on behalf of, the infected and affected community.

Paragraph 45
The message which we want to convey in the strongest terms is that the engagement exercises undertaken by the IBCA have been, in our opinion, shallow, meaningless and 'for show'. We are left with the opinion that the IBCA has been careful to take a range of steps to ensure that, should they come under scrutiny, they can point to dozens of meetings with campaigners, reems of correspondence with infected and affected people and the appointment of user consultants to show that the community has been involved in the IBCA's decision making processes. Those steps however, are worthless when one realises that no regard whatsoever is being had to what the infected and affected people have to say.

Paragraph 46
The compensation scheme has been, since its announcement on 21 May, a pre-determined framework to which only the illusion of collaboration with the community has been attached.

Paragraph 56 (d)
Rather than single-mindedly pressing ahead with the case manager led system, consider how applications might be processed more quickly if you simply allowed us to instruct our solicitors to prepare our claims and declaration forms and submit them directly to an assessor. It seems to us that this might have the effect of immediately and dramatically increasing the IBCA's ability to process claims whilst also potentially saving a significant amount of the planned expense on those case managers.

Paragraph 57
On 20 May 2024, the prospect of giving another witness statement to the Infected Blood Inquiry seemed so completely improbable that it was inconceivable. It is a mark of how poorly the Government has responded, that the Inquiry has felt compelled to issue further Rule 9 requests. We are glad that those Rule 9 request have been issued; our experience of dealing with Government is that they will only change course when they are compelled to do so, or subject to sufficient scrutiny in a public forum.

Nicola Leahey [LINK]
Paragraph 2

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

Paragraph 4
Sir Brian recommended that the compensation scheme be delivered by an ‘arms length body’ (ALB). The ‘Infected Blood Compensation Authority’ (IBCA) was established. In my mind IBCA does not seem to be an ALB. I have been fortunate to attend meetings with both groups, my impression is that Sir Robert Francis and David Foley do not appear to have the control or authority I would have expected. When I have asked questions in the IBCA meetings they often reply that they need to ask the Cabinet Office. Could this be because they have been left trying to implement a compensation formula that was designed by a government committee, an ‘expert panel’ behind closed doors, a committee that we had no representation on and who’s minutes have not been made available despite many Freedom of Information (FOI) requests?

Paragraph 5
My most recent concerns are about the alleged reports of the government trying to silence our community to avoid embarrassment over the delays in the release of compensation. I fear that the same institutional defensiveness and groupthink that caused the original scandal's cover-up are now hindering the scheme.

Glenn Wilkinson, Contaminated Blood Campaign [LINK]

Paragraph 4
We have faced such a profound level of obfuscation that we felt we had little choice but to help promote a legal challenge on the Government's decision making. This has involved many meetings, hours and days of work, providing evidence and support which has led to a JR pending against the Government. After the highs of the publication of the Infected Blood Inquiry report, we never thought we would need to support a legal action against the Government, and this is certainly not what we expected nor wanted to do, but sadly we felt we had no choice if we were ever to stand any chance of securing justice for the majority within our community.

ANON - Anonymous Witness W7758 [LINK]

Paragraph 5
The problem is nothing suggested to IBCA is listened to by them. There was one instance where I was listened to ... Any other suggestions however they have totally gone the other way on and done their own thing, not listening to the people at all.

Paragraph 8
IBCA have a social media presence but they don’t answer any of the questions the community ask them on those platforms, have suggested that once a week they go through the questions and provide a response to the ones they can respond to.

Paragraph 12
People are telling me they are upset and nervous and checking social media daily and even hourly for news. Anxiety levels are rocketing to levels people have not experienced before,

people are crying, unable to function, unable to eat, feel sick, feelings of loss, trauma and being retraumatised, a number of people have said to me they have been getting pruritus', urticaria, itching and welts under the skin, people are in fight or flight mode. Physical wellbeing is low, people are at a low ebb feeling that all the hard work they have done campaigning has been for nothing.

Paragraph 20
I remember in one meeting with Sir Robert Francis in October 2024 I asked would I still be sat here in October 2025 waiting to be paid and he indicated that all infected people would be paid by April 2025, well clearly with the numbers so far that is not going to be the case.

The Forgotten Few [LINK]

Paragraph 34
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 twenty steps back. Everyone feels stressed and anxious; this is why it feels as if we're back to the MacFarlane Trust days.

Denise Turton, Tainted Blood Parents [LINK]

Paragraph 10
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. There is no recognition for the impact a death of a child has on the rest of the family and I think that is why IBCA are not involving parents who lost young children. The tariff is very unfair but it has been set and as far as IBCA are concerned that's the end of it. Lee had his childhood and future taken away but none of this is considered nor will it be appropriately recognised.

Paragraph 15
There has been no real involvement from the Infected or Affected in any actual "decision making". The decisions in connection with compensation for those who had lost young children has already been made without input from us or our legal representatives and I cannot see that it will be changed. In fact, we have had no involvement in decision making whatsoever.

Paragraph 18
It has been very stressful and quite overwhelming. We cannot ask any questions and we have not got any answers. There is nothing I can say to the parents who have lost children because it has already been decided. The trust that we had in the government that was built up during the inquiry is completely gone. It has been shattered due to the approach to compensation. We do not trust the government to do anything in our best interest.

Richard Newton, Tainted Blood Affected Siblings and Children [LINK]

Paragraph 20
During the meeting on 8 October, we raised that the line Nick Thomas-Symonds gave in letters was generic. We had encouraged our members to write to their MPs, who then

contacted Nick Thomas-Symonds, who sent back a standard response which we found insulting. He would tag on a line about ‘*siblings*’ and ‘*care awards*’; he continuously repeated that statement in everything that he said. He forgets I’m a core person in a group of 430 people. When they all received a response, it was the same response that everyone was getting from their MPs.

Paragraph 32
After such a horrifying and damning, yet very welcome report from Sir Brian, the very last thing victims thought they would be doing was campaigning themselves and fighting again to be heard.

Tim Wratten, the Fatherless Generation [LINK]

Paragraph 8
we firmly believe that IBCA must speak with our solicitors who have been excluded from virtually all the meetings. Whilst we can express what we want as a group our solicitors need to be involved so that they can advise us and assist IBCA in building better communication and trust that has been lost by the community.

Paragraph 14
The way the Government and IBCA have gone about the process and the resulting tiresome and unproductive arguments have added to the mental strain of those infected and affected and have compounded the delays. Members of the affected community to include widows of the infected have died and are dying.

Sean Cavens [LINK]

Paragraph 9
There is a lack of transparency about how and why decisions have been made. There has been a lack of information published about the reasoning of the expert group appointed by the Government and chaired by Professor Sir Jonathan Montgomery in fixing the compensation tariffs. I do not think that they have sufficiently taken into account the findings of the Inquiry and its expert groups.

Paragraph 15
When the Inquiry final report was published on 20 May, I felt that the Inquiry had taken the time to listen to us and that we had been vindicated. The recent actions of Government make me feel as though they have not paid attention to the criticisms made in the report, to the point where I question whether they have even read it. 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. I do not know whether I will be one of the first to be able to make a claim based on length of time since infection as I was infected when I was one year old, or whether I will be one of the last to be able to make a claim because I am aged 43 and therefore one of the younger infected people. I am completely knackered and just want a resolution.

Paragraph 16
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.

Scottish Infected Blood Forum [LINK]

Paragraph 12
The charity is not currently funded by any grants and operates solely on the goodwill of its trustees, staff and volunteer members. The volume of work arising after the Inquiry final report has increased exponentially at the same time when there was no funding. This has caused, and is continuing to cause, considerable stress on the charity, its staff and volunteers. What amounts to a full-time post, is being carried out by our Manager, who already has full-time work and job commitments. He undertakes work in his spare time, in lunch breaks, in evenings and at the weekend, and takes annual leave and unpaid leave to attend meetings on behalf of SIBF during a working day. This is understandably untenable.

Paragraph 15
The meetings were declared at short notice. The initial meeting with the Labour Paymaster General was abysmal: representatives were strictly allowed only 4 or 5 minutes to address many specific questions that officials directed/restricted our attention to. In our view the meeting was woefully deficient and all participants from other charities and groups expressed the same discontent.

Paragraph 20
It is very concerning that Government continues to act and exhibit the same themes of lip service for the infected and affected communities across Scotland and the UK. They seem to engineer their policies and decisions in advance and then engineer managed and controlled consultation processes to back-up their already drafted conclusions.

Paragraphs 28-30
Charities and advocacy groups should be properly funded NOW. This funding should be BACKDATED to May 2024. Failing to do so facilitates the Government continuing to get ‘blood out of a stone’.

There should be properly funded and transparent legal assistance given to the infected and affected victims. The contrivances of Government to date in this regard have been appalling. Funded legal assistance should be provided to ensure that legal representatives are able to provide advice on the content of regulations and importantly can be involved in meetings where technical updates are given from Government and/or IBCA.

There should be adequate transparency by UK Government, Cabinet Office officials and IBCA. The irony is that the candour they seek to promulgate is nowhere to be seen since the Inquiry report was published. Indeed, staggeringly, quite the contrary.

Bruce Norval [LINK]

Paragraph 5
The biggest problem with the design of the scheme has been the failure of the Government to establish medical and legal expert panels as envisaged by the Inquiry in its second interim

report. In January 2024, nine months after the Inquiry's second interim report in April 2023, John Glen MP (Paymaster General), announced that the Inquiry had appointed an Expert Group to advise on the Government's response to the Inquiry's Second Interim report recommendations regarding compensation. The role of this group was not clear.

Paragraph 7
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.

Paragraph 14
I believe that the majority of the concerns and depressive angst could be solved by introducing members of the Inquiry's expert groups to inform the next set of Regulations. I have faith in Sir Brian and in expert panels. Their responses were thoughtful, measured, considered and well evidenced. My only criticism would be the lack of paediatric consideration in viral exposure. The second set of Regulations should be handed to Sir Brian Langstaff and the Inquiry should be allowed to go through them with their experts having been involved and to give them credible feedback.

Haemophilia Scotland [LINK]

Paragraph 5
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.

Paragraph 14
Following publication of the Inquiry report and the related announcements from government, our organisation and others like the Haemophilia Society and Haemophilia Northern Ireland received significantly increased approaches from our members looking for help in understanding what was proposed by way of compensation and the process involved. In the absence of information from IBCA and confusing documentation from government, individuals turned to us for help. As a small organisation with only two full-time staff we struggled to respond. The support we provided was to the detriment of our other work. A situation that cannot be sustained without significant risk to the future of our organisation.

Paragraph 20
On 8th July Haemophilia Scotland wrote to the new Minister with responsibility for the government's response to the Infect Blood Inquiry – Minister for the Cabinet Office, Nick Thomas-Symonds MP (WITN7754009) drawing attention to the necessity within the Victims and Prisoners Act 2024 to put into place regulations on the compensation scheme by 24th August 2024. We expressed our view that the scheme as then proposed fell considerably short of what the Infected Blood Inquiry and Sir Robert Francis Framework Report had recommended. We were critical of the lack of consultation with the infected community in preparing the scheme.

Paragraph 32
On 5th/6th December the Cabinet Office issued what they termed a “targeted” engagement on the criterion to be applied for those seeking an additional autonomy award under the supplemental route for unethical research (WITN7754019). This was another example of an unreasonable timescale within which voluntary bodies were asked to respond to consultation. We were given just 14 days to respond, during which time we had to consult with our members. We responded to the consultation via the Infected Blood Inquiry Response Team on 19th December 2024 (the closing date for responses) (WITN7754020) drawing attention to flaws in the rationale being adopted. None of the comments we made apart from the inclusion of the Cardiff Haemophilia Centre within the list of institutions where unethical research was deemed to have taken place were accepted. It is notable that this is the only aspect of the supplementary route on which the government has engaged.

Paragraph 56
The approach of the UK government, with few exceptions, has been unhelpful throughout. For the infected blood community it has felt that there has been an impenetrable wall preventing the community from engaging and understanding what is to happen to them. We have returned to a paternal “we know what is best for you” approach. We feel in a chicken and egg situation where the Inquiry recommendations on 4(b) (Cultural Change) and 5 (Ending the defensive culture in the civil service and government) need to be implemented before we can move forward.

Paragraph 79
The Inquiry Report foresaw a compensation scheme where those infected and affected were an integral part of the decision making. What we have is something that is as far removed from that concept as it could be. Everything is decided behind closed doors. That has to change.

Paragraph 89
The UK and devolved governments should move swiftly to implement recommendations 10 (a)(ii) to 10 (a)(iv) on patient advocacy. This would allow the organisation listed at 10(a)(ii) to continue to provide assistance to the infected and affected in support of the early payment of compensation by the IBCA. As yet no one from government has approached the named organisations about this whilst we continue to field questions arising from the lack of clarity over the government’s proposals.

Carolyn Challis [LINK]

Paragraph 31 We don’t have time or the energy to keep fighting for justice.