WRITTEN SUBMISSION ON THE INFECTED BLOOD COMPENSATION SCHEME ("IBCS") ON BEHALF OF THE CORE PARTICIPANT CLIENTS REPRESENTED BY THOMPSONS (SCOTLAND)

1. Introduction

1.1 The core participant clients represented by Thompsons (Scotland) once again welcome the opportunity to make submissions to the Inquiry, on this occasion in connection with the matters which have given rise to the oral hearings which took place 7th and 8th May 2025 and associated evidence, in particular the IBCS and the Infected Blood Compensation Authority ("IBCA") and the events relating to their creation and operation. Indeed, those clients are appreciative that the Chair of the Inquiry had the foresight to keep the Inquiry open to enable such hearings to take place, that foresight having been based on the reasonable anticipation that the UK Government would fail to implement the Inquiry's recommendations in full, as it had undertaken to do and that, to the extent that that were implemented that that would be likely to be undertaken in an unsatisfactory manner, likely causing further harm and distress to the traumatised infected and affected community. One of the lessons learned by the Inquiry was that this was the consistent pattern of how this community had been treated by government in the past and indeed the present. It was entirely foreseeable that this would be the pattern for the future, which it unfortunately has been.

1.2 It is apparent from the hearings and the written evidence provided to the Inquiry ahead of the additional hearings that the concerns regarding the IBCS and IBCA are multiple and varied, cutting across many elements of the Scheme. Those core participants represented by Thompsons Scotland welcome the opportunity given to them by the Inquiry to have their voices heard regarding not just the concerns that have arisen, but in respect of the

suggestions that they have to make in order to bring about real and positive change, which is needed as quickly as possible.

1.3 Past, present and by extension future issues with the structure and operation of the IBCA have been clearly set out in the evidence available to the Inquiry. The panel comprised of infected and affected individuals and charitable representatives which gave evidence on 7th May 2025 set out what we submit were clear and reasonable proposals as to how steps might be taken to solve the problems which clearly exist with the scheme. There would be little to be gained in simply rehearsing those here. Instead, this submission focuses on:

(a) recommendations which are of particular importance to the client base on whose behalf it is submitted;

(b) reflections on the evidence heard by the Inquiry and its findings and their implications for the way that the IBCS has operated and should operate in future; and

(c) areas where we feel that more detailed submissions would be of benefit to the Inquiry in compiling its further reports on the matters which have been canvassed in its most recent hearings and associated evidence.

1.4 In the course of the hearings, government witnesses gave numerous assurances that they would reconsider positions and/or revert to the Inquiry following further review and enquiry. These submissions have been drafted without sight of those further details being provided and on the basis that the issues raised for reconsideration are being adequately and properly addressed. The core participants upon whose behalf these submissions are made would respectfully seek the opportunity to provide further submissions arising from any further information provided by those witnesses.

1.5 Further, we note that the hearings took place when relatively few cases had made their way through the IBCA system and that the full implications of the relatively recently enacted 2025 Regulations are yet to manifest themselves

on actual claims. The full extent of the issues with the Scheme, in particular of aspects which are introduced by the more recent Regulations (such as the Supplementary route) have yet to be experienced. As it set out below, experience to date does not create a great deal of confidence that issues will not arise or that, when they do, they will be dealt with in a satisfactory way. Thus, given the apparent need for the Inquiry to continue to be a presence for enforcement of its recommendations (including those in its second interim report), we would urge the Inquiry to continue to follow its current approach of continuing to be available as a means of monitoring and evaluating the current Scheme and its progress.

2. The issues

A. The conception of the Scheme

a) General

2.1 In our submission, it is important that the Inquiry documents clearly the failures associated with the way in which IBCS has come about in its further report. It is important that the inadequacies of that process are exposed for public consumption, that the harm which they have done to the infected and affected community be properly catalogued and recognised and that the details of the various failings be spelt out, so that they can be eradicated and avoided in the future operation of IBCA.

2.2 One important aspect of the evidence which has been heard was a justifiable loss of trust in the UK Government based on its approach to date, as well as the consequent effect this has had on trust in IBCA, the rules and operation of which have been so completely controlled and are thus so intimately connected with decisions taken within the Cabinet Office. The Inquiry must do

what it can and must recommend that the UK Government and IBCA do what they can to recognise this loss of trust and address it.

2.3 The following represent some of the ways in which the failings have manifested themselves and submissions as to why they have occurred.

b) Delay

2.4 When the Infected Blood Inquiry published its second interim report, over 2 years ago, on 5 April 2023, those represented by Thompsons Scotland could not have anticipated the need to return for further hearings regarding the issue of compensation in July 2023, let alone in May 2025, two years after the Chair of the Inquiry recommended that a compensation scheme be set up and begin work before the end of 2023.[1] The evidence heard by the Inquiry makes clear that need for the hearings in May 2025 arises in circumstances of deep frustration, mistrust and disappointment on the part of the infected and affected caused by the UK government's (both past and present) response to the Inquiry's report and the setting up of the Infected Blood Compensation Scheme.

2.5 The effect of the way that the UK Government has gone about setting up the IBCS, against a background of existing mistrust, consistently compounded harms caused by government over decades should not be underestimated. As Mr Andrew Evans put in his oral evidence to the Inquiry: *"the damage caused* [by the way that the IBCS has been set up] *deserves its own compensation scheme".*[2]

2.6 As is borne out by the Inquiry's main report, the history of the infected blood scandal is one of multiple, compounding harms being inflicted upon the infected and affected community. There is widespread, deep and wholly understandable concern, anger and mistrust of the government, in particular

[1] IBI Second Interim Report, 5 April 2023, Recommendation 18
[2] Transcript for 07/05/2025; 26/13-16 (Andrew Evans)

the UK Government, borne of decades of obfuscation, denial and repeated and extensive delays. Hopes have been raised, only to be dashed, again and again, with such experiences perhaps even more profound and pronounced after the publication of the Inquiry's reports.

2.7 In his oral evidence to this Inquiry, James Quinault said that, by the time he took up his appointment in the Cabinet Office in the summer 2023, the decision that the UK government solely would determine the design and structure of the compensation scheme, including the eligibility criteria and tariffs had already been taken. In other words, by June 2023, before the Inquiry sat to hear additional evidence relating to the compensation scheme, the decision had already been taken to ignore the fundamental premises for the scheme as recommended by Sir Brian Langstaff in his second interim report.

2.8 And yet, on 26 July 2023, the then Prime Minister, Rishi Sunak told the Inquiry that *"if the Government had just pre-emptively acted before the conclusion of this Inquiry and reached a conclusion that people were unhappy with, I think most people will have said, 'Well you set up an independent inquiry, it is right that you should let that Inquiry make recommendations to you before deciding what to do'"*[3]. Despite this, decisions had already been made, and steps were already being taken to put in place a scheme that ran contrary to some of the core principles of the recommendations. Little meaningful explanation has been provided by any government as to how that position was reached.

2.9 It does not appear to have been with the intention of minimising delay; Sir Robert Francis told the Inquiry that it was the Cabinet Office's own planning assumption when IBCA was finally set up with Sir Robert and David Foley appointed that it would take 12-18 months before work on compensating the community would start.[4] We submit that the evidence suggests that the oft-repeated phrase that the government is working 'at pace' is contradicted by the evidence. It appears that the reason that anyone has started to receive compensation is the endeavour of Mr Foley and Sir Robert Francis who

[3] Transcript for 26/07/23; 23/10-15 (Rishi Sunak)
[4] Transcript for 08/05/25; 14/5-17 (Sir Robert Francis)

recognised the need to 'press on' in light of their particular understanding of the needs of the community. At each turn, there is little evidence to suggest that government itself has been working 'at pace', let alone a pace that reflects the aging and ill demographics of the infected and affected communities.

2.10 It appears clear from the evidence heard by the Inquiry that, despite plans for recruitment going forward, there are justifiable concerns about the likelihood that the work of IBCA will be able to proceed any more quickly in the future. Along with the increased involvement of legal representatives in claims, we propose that IBCA should sub-contract out work to IBSS staff to enable progress to be made with registering cases and to allow IBCA to continue to process cases more quickly. A particular priority should be giving to registering and processing the claims of and providing interim compensation for cases of living infected people who have never before received any support payments, including those who are suffering from HBV.

c) Advisory structures

2.11 A key aspect of the lack of trust which has underpinned the failings of the IBCS to date can be found in the way in which the UK Government commissioned and has relied upon advisory structures contrary to the way in which the Inquiry recommended they should be constituted and operate. As one witness put it:

"Government did not trust us to talk to the Montgomery panel, in fact even to sit on it, like we did with the financial reviews and the clinical reviews in Scotland which brought positive results that resulted in a 97 per cent satisfaction rate with what SIBSS was offering.

So not only do we face this situation where we don't trust Government, but Government has clearly indicated it doesn't trust us. And there are people who

are very able in this room who could have offered advice, experience, knowledge and expertise in the drawing up of these tariffs that have become so controversial".[5]

2.12 The basis upon which it was entirely predictable that a lack of engagement with the infected and affected community result in a collapse of trust was not only the Inquiry's own report but in the evidence of the relative success of other similar groups where such effective, active engagement had taken place (such as the Scottish Government's Financial and Clinical Review groups).

2.13 As regards advisory structures, in its second interim report at page 22 the Inquiry stated that:

"It should be for the Chair to decide who to appoint. Lawyers who have been involved in this Inquiry and have thus acquired a familiarity with the principal infections, their impacts and their causes would be well placed to apply. Since both panels are there to advise on the scheme of banding and levels of award which are appropriate, and if adopted by the Chair their views will have a direct impact on beneficiaries of the compensation scheme, the panels should be expected to talk to, engage with and consult widely with beneficiaries"

2.14 The evidence heard by the Inquiry demonstrated that the issues with the IBCS were heavily rooted in the way in which the UK Government had gone about consulting on the possible scheme, in particular the secrecy which continued to surround the formation, composition and work of the expert group which was convened under Sir Jonathan Montgomery. The Inquiry should recognise in its supplementary report that the formation of this group contravened the recommendations made by the Inquiry as to how it should be constituted, involving expert lawyers (with knowledge of the scandal and the reasons for the scheme being recommended in the first place) and clinicians as part of its expert panel and with full engagement with the infected and affected

[5] Transcript for 07/05/25; 12/20-13/7 (William Wright)

community for whom the Scheme was being designed. The failure to follow these recommendations and the evidence which the Inquiry has heard about the work of the group, conducted largely in secret and without any apparent understanding of or regard for the evidence heard by the Inquiry has not only given rise to justified misgivings on the part of the infected and affected community but is also the fundament of the considerable issues which have been experienced by those who have had dealings with the Scheme to date.

2.15 The Inquiry's apparent thinking in recommending that these processes be followed was to seek to ensure that the Scheme would avoid the mistakes of the past by seeking to imbed the experiences of the infected and affected community and evidence of them heard and acted upon the Inquiry in its very being. That that did not happen was the root cause of its failures to date. We submit that the evidence shows that the formation of the group was undertaken in deliberate contravention of the Inquiry's careful recommendations in this regard.[6] In fact, the Government's stated intentions to seek expert advice and to seek to rely on the evidence heard by the Inquiry could easily have both been achieved by consultation with the Inquiry's own experts, who had provided helpful and comprehensive advice about relevant matters, in particular relating to losses via the HIV, hepatitis and psychosocial group reports.

2.16 We submit that it can be reasonably inferred that the group was formed as it was (as an advisory group to government and not to the Scheme) to allow the UK government to seek to undermine the Inquiry's recommendations, as opposed to having to face up to them and the evidence on which they were based in a room with those who represented the people for whom it was to be designed and the essential input which would have been provided by those people themselves.

2.17 Further, it should be recognised in the Inquiry's report that the reality of this group's constitution and work represent deliberate misrepresentation on the

[6] Transcript for 08/05/2025;112/3-13 (James Quinault)

part of the UK Government in its planning in this area. Whilst purporting to excuse failures to act on the recommendations of the Inquiry in its second interim report by a purported desire to take account of the Inquiry's findings in its final report, the UK Government was, in fact, setting up its own compensation scheme without adequate regard to the second interim report and without any actual intention to seek to rely on any relevant findings in the final report. Details of the Scheme were based not on the Inquiry's final report – they could not have been given the timing of its announcement shortly after the publication of the Inquiry's final report. Instead, what the UK Government intended to do was set up its own scheme, concocted in secret by faceless individuals who had had no experience of the evidence upon which the recommendation to set up the Scheme was based. In following this deliberate course, the UK Government fully intended once again to mislead the infected and affected community and indeed the Inquiry in its claims that the Scheme would be rooted in what the Inquiry had found.

2.18 The result of this course of action is that it was wrong for civil servants to use the outputs from the Expert Group as the basis for so much of the policy development and decisions underpinning the genesis of the Scheme. This has manifested itself in aspects of the Scheme being at variance with the evidence which the Inquiry heard and accepted, for example:

(a) The evidence heard by the Inquiry about the many and varied extra hepatic manifestations of HCV infection, the effects of treatment for it should have instructed the way in which the HCV tariffs were set;

(b) The evidence heard by the Inquiry about the inadequacy of the crude, hepatic banding for the categorisation of HCV infection use by the Skipton Fund and the need for these categories to be revisited, including in the evidence of the Scottish Government's Financial and Clinical reviews in the aftermath of the Penrose Inquiry should also have informed the approach in this regard;

(c) The evidence heard by the Inquiry about the many instances and manifestations of unethical research ought to have informed the approach to this part of the Supplementary award;

(d) The clinical basis for and the success of a self-assessment model in the Scottish Infected Blood Support Scheme ought to have informed the approach to the way in which eligibility and banding were approached in IBCS;

(e) The importance of legal and charitable support in the slow progress achieved by campaigners on behalf of the infected and affected over the years should have informed the way in which they became involved in the conception and operation of the Scheme; and

(f) The evidence about the consequences of lack of engagement of the infected and affected community in the conception and operation of the Alliance House organisations should have made clear the potential pitfalls of the non-consensual approach which has been taken.

d) Lack of meaningful engagement

2.19 The experiences of delay have been compounded by a lack of transparency and accountability to the infected and affected community since May 2024. In those circumstances, it is hardly surprising that there is scepticism about the government's current and previous intentions. The concerns regarding the Scheme and how it has come to be introduced are palpable. These concerns go not just to the past, but to the future; as a result, as one witness to the Inquiry said, "*what we've instead ended up with is a situation where trust and confidence, both in Government and, unfortunately, to a certain extent in IBCA, has collapsed, and that's why were all here today. It's a lack of trust and confidence*".[7] This has occurred despite the theme of trust having played a key

[7] Transcript for 07/05/25; 12/15-19 (William Wright)

part in the recommendations of the Inquiry about the involvement of the infected and affected community in decisions that affect them.[8]

2.20 A user advisory board to IBCA should be set up as a matter of priority, but this should not be seen as a sticking plaster to cover the lack of community engagement thus far. The role of the advisory board ought to be clearly defined and the membership must ensure the diverse breadth of experiences of the community are properly reflected. But community engagement must not begin and end with the advisory board; the infected and affected community must be *"inhabit BCA from the top to the bottom"*[9], reflecting the considerable experience and understanding of the unique and enormous nature of the infected blood scandal. This will have the effect not only of promoting the buy- in of the community to, promoting trust and minimising further harm but also to imbed in the processes of the IBCA a living embodiment of the evidential basis upon which it was founded, maximising the changes that its aims and practices are rooted in the harms for which it was set up to provide redress. The Chair of that user advisory board be afforded rights of attendance and the ability to speak at IBCA board meetings to reflect its views, opinions and priorities.

2.21 The comment made by Sir Robert Francis[10] and the commitment made by David Foley of IBCA in their oral evidence that engagement with the infected and affected community is listened to and acted upon[11] is welcome. It was a feature of evidence heard by the Inquiry that the UK Government sought to emphasise limited engagements with the community as being evidence of a satisfactory or responsive level of engagement. For example, references were frequently made to the changes made to the Scheme regarding payments to be made to siblings or the December 2024 consultation on the unethical research award, which were claimed to have resulted from engagement with

[8] In its second interim report at page 19, the Chair of the Inquiry had stated that *"It is important that decisions about those who should receive compensation should not be made without them.*

[9] Transcript for 07/05/25; 92/21-93/2 (William Wright)

[10] Transcript for 08/05/2025; 77/24-78/1; 80/16-81/20 (Sir Robert Francis)

[11] Transcript for 08/05/2025; 81/21-82/12 (David Foley)

the community.[12] In fact, the weight of the evidence is that these examples are outweighed considerably by evidence of inadequacy in this regard. The evidence heard by the Inquiry was full of examples of lip service being paid to community engagement.[13] The December 2024 consultation was, in fact, very limited and not acted upon.[14]

2.22 It is imperative that the bodies involved in the continued set-up up and administration of the compensation Scheme must be called upon to account for the way in which they have listened to and acted upon engagement with the applicant community. The IBCA needs to be made to be more explicit in disclosing analysis of data on which conclusions decisions which purport to be derived from consultation or engagement with the infected and affected community are based. Thus, the Inquiry should recommend that both the UK Government and IBCA should be under an obligation to account clearly and regularly both in public and to representative organisations how they intend to act upon reasonable contributions made about their operation, with reasonable deadlines and to explain how these commitments have been met, all in the interests of transparency and co-operation which, in turn, will foster greater confidence and wellbeing.

d) Independence

2.23 As Ms Caz Challis put it in her oral evidence to the Inquiry, the sequence of events has (justifiably in our submission) lead to the infected and affected feeling that those who cause the disaster in the first place *"are still marking their own homework".*[15]

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[12] See for example https://www.gov.uk/government/publications/infected-blood-compensation-scheme/government-update-on-the-infected-blood-compensation-scheme-html#scheme-design
[13] WITN7754001_0011 para 34 (John Dearden)
[14] WITN7754001_0010 para 32 (John Dearden)
[15] Transcript for 07/05/2025; 28/14-19 (Caz Challis)

2.24 The evidence herd by the Inquiry in recent weeks makes it clear that the Cabinet Office (with assistance in identifying experts from the Department of Health) have taken total control over the consultation on, rules governing and the operation of the Scheme. There has been little, if any, accountability for that control. It has taken the Inquiry convening further hearings a year after its final report was published to try to obtain it. The lack of engagement with the infected and affected community is addressed elsewhere in this submission. The Inquiry must re-iterate the important recommendations that (a) IBCA requires to be a proper arms lengthy body, independent of Government and accountable to Parliament[16] and (b) that the provisions of recommendation 12(d) relating to parliamentary committee oversight by the Public Administration and Constitutional Affairs Committee of the compensation process needs to be actioned immediately.

2.25 In his final report, the Chair optimistically predicted that:

"I anticipate that within the next 12 months the Government will have considered and either committed to implementing the recommendations which I make, or has given sufficient reason, in sufficient detail for others to understand, why it is not considered appropriate to implement any one or more of them. During that period, and before the end of this year, the Government should report back to Parliament as to the progress made on considering and implementing the recommendations. I anticipate that at that stage I should be able to tell the Minister that the Inquiry has fulfilled its terms of reference. But I shall do so only if I am satisfied that there is no further role I can usefully play in preventing delay. I also recommend that the Public Administration and Constitutional

[16] Transcript for 08/05/2025;111/8-18 (James Quinault) – it is clear that despite the recommendations of the Inquiry in this regard that this was deliberately not done by the UK government on the basis that to do so would be "unprecedented". One might well argue that that it is very much inherent in the Inquiry's recommendation that the unprecedented situation called for an unprecedented response

Affairs Committee ("PACAC") should review both the progress towards responding to the recommendations, and, if they are accepted, towards implementing them."[17]

2.26 Numerous important aspects of the Inquiry's recommendations across its reports have not been implemented by the UK Government, as this submission seeks to highlight. There has been no real oversight of the failings in this regard, contrary to the aspirations of the final report. This submission does not go as far as to call for a complete overhaul of the entire system of compensation. The actions of the UK Government have rendered any such call counter-productive, given the likely further delay and harm which would be caused by starting from the provisions of the Inquiry's second interim report again. That does not mean that aspects of the Inquiry's recommendations in that report and in its final report do not need to be revisited immediately to seek to provide some level of confidence that the existing system will not be allowed to proceed without appropriate oversight and control.

Civil servants

2.27 Connected to the legitimate concerns about the lack of independence of the IBCA is the continued involvement of civil servants in its conception and operation. The involvement of civil servants in the operation of the Scheme including on its Board was amongst the reasons why Mr Burgess described the new Scheme as being like *"the MacFarlane trust on steroids"*.[18] Although certain assurances were given that the way in which the IBCA would work would enable a degree of independent engagement of its staff[19], these

[17] Inquiry final report, volume 1, page 282
[18] Transcript for 07/05/2025; 73/14-74/14 (Alan Burgess)
[19] Transcript for 07/05/2025; 124/19-125/3 (Nick Thomas-Symonds); Transcript for 08/05/2025; 7/21-10/10 (Sir Robert Francis)

concerns are likely to remain. They are very legitimate concerns, in our submission, based on the copious evidence heard by the Inquiry about the key role played by civil servants (both administrative and medical) in seeking to undermine the legitimate claims of the infected and affected communities and underplay the State's role in their infections over many decades.

2.28 The independence of the IBCA was consistently described as *"operational independence".*[20] In our submission, this is a misleading phrase designed to conceal the reality that (a) the operational parameters within which IBCA works is, in fact, almost entirely prescribed by Government and (b) the executive and administrative sides of IBCA appear to be almost entirely controlled by civil servants. It is, in fact, not an independent body at all.

2.29 The Inquiry should recommend that the IBCA move immediately to employing its own staff who are not from the civil service and that Board positions be occupied by non-civil servants to seek to maximise its independence. This must include representatives of the infected and affected community on the Board who must *"inhabit IBCA from top to bottom".*[21]

B. Rules underpinning the operation of the Scheme

a) Self-assessment

2.30 The amount of material which needs to be presented both as regards eligibility for compensation and proof to qualify for various awards is excessive. The Inquiry has access to significant evidence about the advantages of self-assessment which underpinned the Scottish Infected

[20] Transcript for 08/05/2025; 11/25-13/13 (David Foley)
[21] Transcript for 07/05/2025; 92/21-93/7 (Bill Wright)

Blood Support Scheme, including the endorsement of this approach by clinicians involved in the consultation exercises which preceded it. [22]

2.31 In this regard, the current IBCS represents a step backwards in the way in which applications are handled. As applicants have submitted before, the efficiency of the Scheme would be likely to benefit from the introduction of a presumption that the basis upon which applications are presented by core participants in the Inquiry is accurate.

2.32 Further moves towards a more trust based, self-assessment approach are set out below.

b) Hepatitis C banding

2.33 It was clear from the evidence heard by the Inquiry that the liver-damage orientated criteria for the allocation of individuals to certain bands for HCV compensation in the IBCS are not only flawed but have been shown by experience to be flawed. As far back as 2015, the Financial review group set up by the Scottish Government in the aftermath of the Penrose Inquiry advocated a health impact as opposed to a liver based assessment. [23] It is, in our submission, essential that it be the Inquiry and not the UK Government which sets the bands to which the hepatitis tariffs are linked. It is only the Inquiry which will be trusted to set these tariffs, not only due to the reasonable scepticism associated with the priorities of the UK Government but also because it is the Inquiry and not the UK Government which has access to a

[22] Those exercises included a Financial Review group which reported in 2015 (HSOC0014638) and a further Clinical Review group which reported in May 2018 (WITN4081029). The former favoured an evidence-based approach to support which minimised assessment which led to the SIBSS being a self-assessment scheme (See HSOC0014638_0012 and 0016). Further, the principle of self-assessment was therefore unanimously endorsed by the Clinical review group (including the medical professionals who sat on it, whose endorsement of this approach was specifically recorded in the Group's report) (WITN4081029, pages 8 to 9). This was found by Sir Robert Francis to work well (Transcript for 11/07/22; 89/1-19 (Sir Robert Francis; RLIT0001129_0014 @ para 1.23)

[23] HSOC0014638_0008

comprehensive body of evidence of the typical harms which are associated with infective hepatitis in this community.

2.34 The updating of the Inquiry's recommendations in this regard to provide a more evidence- based banding system should also allow the basis of the valuations of each level of hepatitis infection to be open to proper scrutiny. As Bill Wright said in evidence, the tariffs have been set and imposed without any test; had the community, including their legal representatives, been involved in a collaborative approach to matters, there would have been an opportunity to understand the basis on which seemingly arbitrary figures have been applied.[24] Not only are the criteria applied to each level flawed but the apparent lack of recognition of the range of harms typically associated with infection with hepatitis are also.

2.35 At present, the Scheme fails to take any or any proper account of the evidence heard by the Inquiry in respect of the extra-hepatic manifestations of (a) HCV infections and, importantly (b) their treatments. As the Inquiry identified, and as was confirmed by the UK Government, initially the Compensation Scheme was to provide for a supplementary route akin to the Special Category Mechanism. The evidence of the Paymaster General as to why that approach was abandoned was unsatisfactory and circular. Mr Thomas-Symonds stated that there were "*certain conditions that meant that people were on the Special Category Mechanism in the support schemes that were already taken into account in the core route. So an example of that would be something like chronic fatigue, for example, which would clearly affect people's ability to work*".[25]

2.36 The Expert Group's Final Report states that:

"some of [the] aspects of people's experiences have already been incorporated into core awards as the advice from the Expert Group is that they affect most people. This is the case in relation to chronic fatigue for all viruses.

[24] Transcript for 07/05/25; 93/22-94/14 (William Wright)
[25] Transcript for 07/05/2025; 157/19-158/7 (Nick Thomas-Symonds)

Others will be less common, but when they arise they will require compensation beyond the core awards. The Expert Group therefore proposes that there should be six groups of circumstances where the calculations of care needs and financial loss should be adjusted to recognise the increased impact that some beneficiaries experience from their disease".[26]

2.37 It is submitted that this approach is fundamentally flawed for 4 key reasons:

(a) The core route is too hepatic clinical-marker defined with little to no guidance as to which 'certain conditions' have been taken into account when setting the infection level definitions. The claim made on behalf of government that these have been taken into account in the tariffs is not borne out by any clear evidence that this is the case[27];

(b) The supplementary route is too narrowly defined and fails to take account of the clear, comprehensive, and detailed evidence heard by the Inquiry in respect of extra-hepatic manifestations of hepatitis infections;

(c) Little, if any, account appears to have been taken in either route of the considerable effects of treatment for hepatitis, in particular treatment with interferon, about which the Inquiry heard considerable evidence of devastating effects. A tariff that seeks to focus on the clinical, hepatic markers, fails to recognise, for example, that some individuals may have undergone multiple rounds of interferon treatment lasting 9-12 months with debilitating side effects on each occasion. Again, the claim by government that these aspects have been taken into account in the core route[28] does not stand up to scrutiny as, as presently set up someone who had gone through 5 Interferon treatments should receive the same as someone who had had no treatment; and

[26] RLIT0002474_0027
[27] Transcript for 08/05/2025;123/1-16 (James Quinault)
[28] Transcript for 08/05/2025;124/2-126/11 (James Quinault)

(d) The supplementary route only gives rise to additional claims in respect of financial losses and care needs whereas the additional non-hepatic manifestations of the infection ought to be recognised as a matter of the equivalent of general damages as well.

2.38 Although it is recognised that a broad-brush, community settlement approach in which the need to undergo individual assessment is welcomed, it is submitted that the approach is both (a) too narrow in the core route, limiting the criteria applied to a recognition of liver damage only where the evidence of the Inquiry was that the consequences of typical HCV infection and its treatment were far more varied and limiting than that and (b) fails to recognise the need for recognition of exceptional individual experience of infection.

2.39 The Inquiry ought to recommend a wholesale revision of the Scheme with detail as to awards (under all heads of claim) which should be made. Though a precise quantification of the financial consequences of this new approach is beyond the ambit of this submission, the new Scheme which the Inquiry should recommend should have the following features:

(a) That figures in the core route should generally be uplifted under all heads to reflect the full range of typical harms associated with hepatitis infection, including its typical mental health (depression), brain fog, chronic fatigue and cognitive impairment related consequences, as set out in the Inquiry's expert report on hepatitis and numerous statements from infected and affected individuals[29]. This report also accepted the association between auto-immune conditions and HCV infection. Again, we submit that these can and should be included in the bandings which are in the core route given the inevitability of there being some effect on an immune system required to fight HCV infection. The capacity for individuals to uplifted into higher bandings to reflect these aspects of the loss should be based

[29] EXPG0000001_0060-0061 (hepatitis expert group report)

on self-assessment, due to the paucity and limitations, in particular, on mental health service provision over the years. It should be noted that the capacity for mental health sequelae to be compensated via an application to via the supplementary route is limited, given the strictness of the criteria applied, which experts have opined will not allow access for many of those who have suffered in this way.[30] Our proposal to solve this issue is that mental health be recognised in the core route awards and that they should be uplifted, on the basis that a considerable level of mental distress can be assumed in any case or, alternatively that the supplementary route to additional compensation due to severe psychological issues be based on self- assessment, as was the case under SIBSS;

(b) That the harm caused by treatment[31] is expressly recognised as a separate injury and compensated as such, with particular uplifted figures being recommended for these aspects of the harm and consequent uplifts in consequential losses; and

(c) That the Supplementary route should not be defined so narrowly as to limit it to certain qualifying conditions (see below).

2.40 The awards for consequential losses ought to be increased for those who quality for the additional impact awards in ways to be specified by the Inquiry in its additional reports based on the evidence which has been heard about the additional harms which are to be expected by those who have suffered from decreased disability and increased care requirements based on (a) the extra- hepatic manifestations of HCV and (b) treatment with Interferon.

c) Financial awards

[30] See NTHT0000059 (letter from the Infected Blood Psychology Service dated 29th April 2025)
[31] EXPG0000001_0059 (hepatitis expert group report)

2.41 We submit that the Regulations relating to the calculation of past and future financial loss and care costs in Regulation 7[32] and the deeming provisions of Regulation 20(7) where a date for change in the severity of infection cannot accurately be established[33] require to be reviewed to provide more equitable results. The Inquiry should recommend that regulation 7 be altered to provide for a more simple calculation as to the financial losses of an individual, with the complex formula under regulation 7 removed.

2.42 As regards the deeming provisions, the Inquiry should recommend that the relevant date for the purposed of the calculation must not involve the date on which the application for compensation is made but must flow from the dates which the evidence shows that developments in an individual's condition occurred.

2.43 In addition, the current percentages applied to calculate deductions are without apparent foundation. It is far from clear as to how they have been arrived at or what medical evidence underpinned these crude measures. The Inquiry should recommend the removal the of the financial loss percentages attached assumed viral impacts over time. A more simple and realistic process would involve the use of the median wage as the baseline upon which to calculate financial loss, without deduction.

d) Awards for children of infected parents

2.44 There is no apparent justification for the awards which are available to the affected children of infected parents. There is significant concern that these are too low and do not take account of the evidence about the significant effect on such children heard by the Inquiry. We invite the Inquiry to undertake or recommend their review.

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[32] See written statement of Benjamin Harrison (WITN7759001) from paragraph 91
[33] See written statement of Benjamin Harrison (WITN7759001) from paragraph 103

e) The Supplementary route

2.45 The full implications of the Supplementary route are yet to be seen in the way in which applications under it will be handled by IBCA. However, we submit that, as currently defined, it is too narrow. It has deviated too significantly from its original purpose, namely allowing applications based not a recognition that the Core route tariffs could not cater for the full range of diverse effects of infection or in the affected community and that a more individualised assessment route would be necessary. The UK Government has claimed that the list of eligible "severe health conditions" has been developed following advice from the Infected Blood Inquiry Response Expert Group. This aspect of the Scheme was originally designed to cater for those whose losses were greater for any reason and invited a greater degree of individual assessment, which would take longer to arrive at but which would take place once the core route award had already been made. The Inquiry should recommend that this original principle needs to be reinstated as its purpose.

2.46 The Government claims that *"The Core route tariffs already take into account most of the severe health conditions that infected people are likely to experience as a result of their infection".*[34] The submissions made elsewhere indicate our view that this is not the case. As far as those whose claims are based on infection with HCV are concerned, the conditions for which compensation is currently paid (both under the injury award and the consequential awards which are dependent on the banding of the injury award) compensate individual only for the liver related consequences of the infection. There is too great a gap between those consequences and the narrow number of "severe health conditions".

[34] https://www.gov.uk/government/publications/infected-blood-compensation-scheme/government-update-on-the-infected-blood-compensation-scheme-html#scheme-design

2.47 It is a logical anomaly that the qualification for the supplementary route attracts no additional impact award when the entitlement to enter it is based on a recognition that an additional injury must have been sustained – further additional injury tariffs not catered for in the core route must be part of this aspect of the Scheme. These should be fixed by consideration of the level of offer by legal assessors within the IBCA process, who should be asked to assess the level of award in a more bespoke way, as the individualised assessment in this route originally contemplated.

2.48 The Inquiry should recommend that the exceptional financial loss calculation needs to be re-assessed. At present, an applicant for these awards would need to provide evidence of higher PAYE earnings or earnings from self-employment than would otherwise be paid under the Core route. This precludes access to these awards for people who (a) as a result of their infection (perhaps in childhood) had a resultant deficit in education or training which precluded entry into a career they would otherwise have entered[35] or (b) even for those who can provide evidence of earnings who assert that they would have changed careers or otherwise earned at a higher rate of income but for their infection. There are numerous applicants who fall into these categories who are unfairly disadvantaged by the current evidence-based system. The Inquiry should recommend that a system, similar to the way in which courts approach such awards (involving the use of employment tables and expert evidence) should be available for such cases.

2.49 Further, the Inquiry should recommend that the UK Governments clarifies its intentions with regard to cases being assessed under the Supplementary route and its implications for the timing of the assessment of claims which have attracted lower priority, such as those of the affected. If core and supplementary route claims are to be processed for the infected living first, this will take some considerable time and will push the infected deceased

[35] This was accepted on behalf of the UK government in oral evidence - Transcript for 08/05/2025;166/10-167/11 (James Quinault)

and affected claims back even further. The current inadequacies of matters taken into account in the Core route (in particular in HCV cases, addressed above) will mean that many will claim on the Supplementary route, given their feeling that the core route has inadequately categories their claims and the full extent of their losses. Though the submissions made above ae designed to try to address those legitimate concerns, the arrangements as they stand will cause further intolerable delays to the affected. Thus, we propose that the living core claims be processed (with new Regulations to better recognise and categories a broader range of harm), alongside deceased infected claims, with and supplementary route applications and the affected's own claims being dealt with thereafter. This will result in some money getting to families more quickly than would otherwise be the case.

2.50 The supplementary route should also be open to the affected their own claims who wish to make a claim that their loss exceeds that which has been awarded to them under the core route, including an additional impact award in their own right.

f) Unethical research award

2.51 We support the evidence of Mr Gary Webster to the Inquiry to the effect that the £15,000 award for unethical research is *"disgraceful"*.[36]

2.52 It is far from clear what this award is meant to provide compensation for. In particular, it is not clear how this award fits with the autonomy award under the Core route which purports to "recognise[s] the distress and suffering caused by the impact of disease, including interference with family and private life (e.g. loss of marriage or partnership, loss of opportunity to have children)". The Inquiry heard copious evidence about the fact that nearly every person treated for bleeding disorders had regularly been tested for various infective

[36] Transcript for 07/05/2025; 40/16-41/3 (Gary Webster)

diseases without their knowledge, did not know the results of those tests and were not informed of positive tests or their implications. Whether those people were involved in formal, published research or not, these were significant components of the betrayal of trust, dignity and autonomy. The current Scheme appears to provide no compensation for this, which can (on the basis of evidence heard by the Inquiry) can be assumed to have happened in all bleeding disorder cases. The current award is derisory and tokenistic, an apparent afterthought on the part of the UK Government, in particular for those who were involved in formal, published research (invariably undertaken and published without their knowledge or consent) and those routinely tested as children (invariably without their or their parents' knowledge or consent), given their value based on their lack of previous treatment and hence exposure to virally infected treatments. The exploitation of patients, in particular children, is what led to patients being described by one prominent haemophilia clinician as "useful material".[37] These highly significant findings on the part of the Inquiry are simply not recognised by the Scheme. The Inquiry must recommend a complete overhaul of this element of the Scheme.

2.53 The evidence heard by the Inquiry was that, in many cases, this aspect of care was of fundamental significance to the infections being contracted in the first place. Further, copious evidence was available to the effect that this factor had the effect of significantly compounding the overall harm suffered by those who had been infected in this way, such was the impact on their trust on the medical profession as well as the impact on them psychologically as a result of the dehumanising effect of this reality.

2.54 As we have submitted to the Inquiry before, we consider that the effect of this aspects of the contaminated blood disaster has been and continued to be significantly underestimated. The presence of this factor in the cases of this involved has, in our submission, significantly compounded all aspects of the harms which have been suffered. Thus, we propose that the Inquiry

[37] Transcript for 01/12/20; 111 - 113 (Professor Ludlam); LOTH0000031_027 (28 April 1980); See also submissions on the subject at SUBS0000064_0762 *et seq*

should recommend that a specific percentage uplift on the entirety of the award should be made for patients who qualify, to be applied as part of the core route award.

2.55 In addition, we are of the view that the way in which the UK Government has gone about defining who is eligible this award has been flawed. The UK Government states on its website that *"Eligibility criteria for the additional Autonomy award is based on research studies referenced by the Infected Blood Inquiry, during the time period where unethical research practices were identified to have taken place."*[38] It appears to have been the approach that the Government has sought to look at qualifying institutions from the Inquiry's reports, when it was never part of the remit or intention of the Inquiry to seek to provide a definitive list of this nature. In any event, it was also part of the evidence of the Inquiry that seeking documentary evidence to support the contention is involvement in unethical research is unlikely to be fruitful where even those who can demonstrate by reference to published research that they were subjects of research of this nature cannot access records to demonstrate it.[39] The dates over which research was deemed to be taking place demonstrate a misunderstanding of the extent of the research which was carried out. For example, by ascribing the period 1974-1984 to the eligibility criteria for an award for those who attended the Edinburgh haemophilia centre, the UK Government seems not to have taken account of the evidence that the Edinburgh haemophilia cohort was *"one of the most extensively studied group of HIV infected individuals in the world"* who were subjected to research into their HIV infections for many years after 1984, without their knowledge or consent.[40]

2.56 Instead, an alternative approach is needed to fit in with the principles underpinning the IBCS and its evidential basis in the discoveries of the

[38] https://www.gov.uk/government/publications/infected-blood-compensation-scheme/government-update-on-the-infected-blood-compensation-scheme-html#scheme-design

[39] This is the position, for example, in the cases of those who were part of the extensively researched 'Edinburgh cohort', used as the basis of medical research published in medical journals but for who no records of their involvement appear to exist

[40] The Edinburgh Haemophiliac Cohort", MRC News, September 1990, no 48; See SUBS0000064_0789 *et seq*

Inquiry. We advocate that a broad brush approach to this issue must be adopted and that the evidence of the Inquiry is to the effect that all children who were treated for bleeding disorders with products which passed on infection should be automatically entitled to a percentage uplift of this nature, based on the evidence demonstrating that it was likely that they were tested and used in this way. Such an uplift might also be framed to include the fact that such children are likely also to have experience more overarching loss as a result of their infection at a time when their bodied were still developing. Adults treated at the identified centres should also be entitle to an automatic uplift. The extent of those uplifts should be fixed by the Inquiry.

2.57 We see no reason why the unethical research award needs to be part of the supplementary route, either as presently designed or as we would suggest it should be. The Inquiry should recommend that it should form part of the core route.

g) The affected

2.58 In her oral evidence to the Inquiry, Ms Mary Grindley pointed out the significant effects of delay in the process which have been experienced. As far as the affected community are concerned, she correctly observed that, if they die before their claim is met, they will get nothing, due to the fact that their claims will not pass to their estates.[41] In his evidence minister and Paymaster General Nick Thomas-Symonds accepted that those with an entitlement to claim would die before they received compensation[42] The system is inviting individuals to apply, as opposed to allowing them to apply when they wish to get into the system. This approach, combined with the clear evidence about

[41] Transcript for 07/05/2025; 42/17-43/14 (Mary Grindley); Transcript for 07/05/2025; 82/17-83/2 (Caz Challis)

[42] Transcript for 07/05/2025; 137/16-19 (Nick Thomas-Symonds)

confusion based on lack of information given by the patient panel gives rise to a clear injustice which must be remedied.

2.59 Mr Thomas-Symonds, in determining where to 'draw the line' in respect of claims brought by affected persons who die before receiving their compensation appeared to put particular weight in respect of his decision on the recommendations of this Inquiry[43] even in circumstances where other recommendations of this Inquiry in respect of the framework and operationalisation of the Scheme have been ignored or rejected. In our submission, that approach needs now to be viewed in light of the delays which have been experienced and the reasonable anticipation on the part of the Inquiry at the time it was made that the compensation scheme would be up and running long before now.

2.60 In order to deal with all of these issues in the current system, we submit that the rule relating to the claims of affected persons passing to their estates should be reversed in new Regulations. The prohibition in that regard was, as the Paymaster General said in his evidence based on the findings of the Inquiry[44]. It was Sir Robert Francis' recommendation that affected claims should pass to their estates.[45] One might say that this was an arbitrary cut-off point in any event, contrary to the normal legal rules that the rights of individual would pass to their estates on their deaths. In any event, the change of circumstances since the recommendation to this effect was made in the second interim report, namely the length of time which it had taken to get to this point (inconsistent with the Chair's general aspirations for the compensation scheme at the time of his second interim report) mean that it could not have been anticipated that this cut-off would result in the injustice which it now inevitably will. Thus, this prohibition must be removed.

2.61 If this option is not favoured by the Inquiry, we submit that the alternative would be to allow claims which have been registered in the scheme (along with the right to register when an applicant wishes to) to pass to their estate based

[43] Transcript for 07/05/2025; 144/25-145/12; 172/25-173/6 (Nick Thomas-Symonds)
[44] Transcript for 07/05/2025; 143/20-144/9 (Nick Thomas-Symonds)
[45] Transcript for 08/05/2025; 62/22-66/10; 94/1-23 (Sir Robert Francis)

on the fact of the claim having been registered and not an offer having been made.

h) 31 March 2025 cut off for support

2.62 It is submitted that the arbitrary cut-off for eligibility for support schemes for the infected or bereaved who are not registered on the national support schemes ought to be revisited. Whilst it is accepted that a date for future loss must be provided in order to allow for calculations of financial loss to be properly undertaken, the Regulations as they are currently stand establish a clear lacuna and result in the potential of significant inequity between claimants and their spouses/partners depending on the date of death of the infected claimant.

2.63 To suggest, as Mr Quinault did in his evidence, that the deceased infected person could make provision for this eventuality in their will, or that their spouse/partner would be able to claim in their own right fails to recognise:

(a) that there will be some instances in which the infected person has not received compensation;

(b) that the infected and affected communities have been given repeated and clear reassurances and guarantees that the support payments would be ongoing and that they are relied upon;

(c) the different basis upon which claims would be made by surviving spouse/ partner on behalf of the deceased and in their own right; and

(d) the inherent delays involved in (i) infected deceased claims; (ii) probate being obtained; and (iii) affected claims.

2.64 There is a clear case, in our submission, for determining that this provision was a mistake and that it should be reversed to ensure that payments continue to be made on an ongoing basis, pending the determination of the infected deceased claim. It can reasonably be assumed that for infected individuals who are in ill health, the possibility, due to this arbitrary administrative rule, that their spouse/ partner would be left without support for an undefined period would be likely to cause significant, unnecessary distress. Its effects may cause hardship. The Inquiry should recommend that that possibility be removed.

i) Cut off dates for qualification

2.65 It is submitted that the cut-off dates for qualifying infections are too narrow and should be revisited and removed. The position as advertised by the UK Government is that higher evidential requirements are imposed on people who were infected after December 1972 for HCV, November 1985 for HIV and September 1991 for HCV infection.[46] These dates are based on the timing of the introduction of screening. It is submitted that this approach is fundamentally flawed and seems to imply that the State's obligation to make these payments is based on a breach of legal as opposed to moral duty. This is not what the Inquiry recommended, nor what was recommended by Sir Robert Francis KC. imposing any evidential obligation on a beneficiary of the scheme is inequitable, based on the likely lack of access of applicants to the necessary materials and the passage of time since these dates. It is far from clear what evidential requirements will be imposed in such cases. The Inquiry should recommend that the UK Government publish details of why these dates have been imposed and how these sit with its commitment to the Scheme being based on a moral as opposed to legal duty to pay compensation.

[46] https://www.gov.uk/government/publications/infected-blood-compensation-scheme/government-update-on-the-infected-blood-compensation-scheme-html#scheme-design

2.66 As far as HBV infection is concerned, the cut-off date of 1972 appears to be based on an assumption that the evidence available to the Inquiry indicated that a test was available from that date which screened out the virus. This is an inaccurate interpretation of the evidence available to the Inquiry, which showed that screening tests introduced at that that were variable in their quality and effectiveness, meaning that individuals continued to be exposed to HBV infection, in particular from pooled products. There is also a flavour in this assessment that the UK Government have misunderstood that the scheme is designed to provide compensation on the basis of breach of moral and not legal duty.

2.67 As far as eligibility for HIV compensation is concerned, the 1st January 1982 cut off date for eligibility for compensation for HIV infection in regulation 3 of the 2005 Regulations must be removed. The inquiry has evidence of infections occurring before that date, in Scotland from 1981 in the cohort of haemophiliac boys infected at Yorkhill in Glasgow via Armour factor VIII concentrate. In that group, there were also at least two people infected after November 1985, namely in November 1986 as a result of the use of Factorate HT.[47] Again, this appears to be based on a misunderstanding of the moral duty basis upon which this compensation is being based, with the focus being on a legalistic approach to liability which does not feature in this Scheme.

2.68 The cut off for HCV infection of 1st September 1991 should also be removed. This is the date at which blood donations started to be routinely tested for HCV in the UK. The issues here relates to (a) the need to rely on evidence of testing, as opposed to the date of putative infection and (b) the assumption (not rooted in evidence) that this testing regime eradicated all HCV infections from blood transfusions, in particular. As regards (a), the Inquiry is aware that the early tests often showed a false negative result for Hepatitis C, meaning that a diagnosis may be identified as falling beyond the final cut-off date for Hepatitis C of 1st September 1991. In some cases, positive results were obtained later

[47] See SUBS0000064_0670 para 4.183

when more sensitive tests became available in 1993.[48] As regards (b), we submit that a focus on the date of infection is equally arbitrary and based on a legalistic as opposed to moral basis for compensation to be paid – the moral case exists if an individual was infected by a transfusion whether testing existed or not. Like with the HBV applicants, such individuals have always been excluded from support schemes. Those with legitimate claims continue to be excluded, despite evidence heard by the Inquiry that it was inequitable that they should be.

2.69 Overall, we submit that the continued application these date restrictions is inappropriate, based on the evidence heard by the Inquiry. Evidence presented to the IBCA should be judged as a basis for eligibility on a balance of probabilities as to whether infection was caused by blood transfusion or blood products (including the applicant's won testimony to that effect) with these inappropriate date restrictions removed.

j) Appeals

2.70 Recommendation 14 of the inquiry's second interim report provided that *"Appeals should be to a bespoke independent appeal body with a legal chair which will reconsider the decision of the scheme in any case appealed to it."* That recommendation has not been implemented.

2.71 It is submitted that the appeal mechanism is inadequate and ill-suited to the matters arising in the compensation scheme. We submit that the Inquiry ought to recommend that its previous recommendation that a bespoke independent appeals body chaired by a judge be revisited and implemented, particularly in light of the complexity of the Regulations and the evidence that has been heard about the inaccurate application of the Regulations even in the small number of cases that have been determined to date. There are complex issues of law

[48] WITN2117005

and medicine and little evidence that the Social Security and Child Support Tribunal is adequately equipped to deal with such particular matters.

The operation of IBCA

a) Clinical assessors

2.72 The Inquiry heard evidence about concerns that clinical assessors employed by IBCA may perform in their roles like those engaged in similar roles in bodies like the Skipton Fund when assessing eligibility for compensation or certain bands of award. These are legitimate concerns, in our submission, based on the evidence of past experience and the lack of clear definition as to the identity or precise roles of these individuals in the new Scheme.

2.73 The Inquiry should order a review of the way in which eligibility decisions are made and by whom they are made. It is far from clear from the evidence as to how credibility will judged in eligibility decisions or by whom, for example in transfusion cases where there is no record of a transfusion. This will become more difficult when the IBCS reached applications in to the non-support scheme registered cases, who have not yet satisfied their eligibility criteria elsewhere.

2.74 The inquiry should reiterate the need for transparency in this regard and for there to be a clear definition of:

(a) The identity of those who will be making such decisions namely claims managers or clinical assessors, with a clear commitment to none of the assessors having been involved in the work of the previous AHOs and clarity on their qualifications for making decisions about hepatological progression, the severity of other conditions which we recommend should be taken into account in banding and their ability to comment on matters such as the likelihood of transfusion;

(b) The balance of probabilities test which will be applied (in both eligibility and banding decisions), the need to assume the applicant's position to be true and how that will work in practice in light of clinical evidence or the lack of it (relating to eligibility, such as evidence of a transfusion having taken place and what evidence will be requires/ consider in banding decisions, such as relating to the level of fibrosis required); and

(c) How and by whom decisions in individual case have actually been reached and why, with clarity on when and why clinical assessors are consulted.

2.75 The Inquiry should recommend that these processes must be set out and published process as part of the IBCA's transparency requirements and in light of justifiable concerns amongst the infected and affected community based on their previous experiences of other AHOs.

b) Representation

Legal representation

2.76 It was a flaw in the conception of the IBCA that it was assumed that internal case managers (who appear also to be the decision makers in the process) would suffice as far as representation for applicants to the IBCA was concerned. It is submitted that this was based on a false economy, which has been proven to be significantly problematic in operative experience and insofar as it has contributed to trust ibn the process being undermined. This must be changed as a matter of priority. The evidence given by the minister was that the decision-making in this regard was based on concerns about the legal costs associated with previous similar schemes, such as miners' compensation. As the minister himself acted there was no reason to think that

such comparisons were apt in this situation.[49] In fact, the evidence available was that much legal support was both needed and had been offered *pro bono* by existing lawyers. Concerns about the legal bill can be offset by a mature, honest conversation with them about the needs of the applicant community and the realistic costs of addressing them. The evidence from those involved in IBCA was to the effect that the input of legal representatives to date had been of great value.[50]

2.77 The 2024 Regulations were and the 2025 Regulations are complex and difficult to understand. The Inquiry has heard evidence of occasions on which claims managers (who are not legally qualified) have simply misinterpreted the Regulations. The closer involvement of legal representatives throughout the process is critical and, as witnesses said, to be welcomed and encouraged.[51] The infected and affected communities must not be at risk of losing any part of their compensation as a result of paying for legal fees. It is submitted that, it is vitally important that claimants can avail themselves of specialist legal advice at no cost, rather than signing up to conditional fee agreements. That legal advice must be primarily available from the firms of solicitors who enjoy recognised legal representative status in the Inquiry, who have access to materials necessary to underpin a claim. The UK Government must commit to their work being properly funded and clearly signposted.

2.78 Funding for legal support must be provided throughout the process. Given the ability of recognised legal representatives to understand the particular issues arising from the compensation scheme, it is submitted that involvement of legal representatives at an early stage in compiling the required evidence to support a claim would be of considerable assistance to the scheme in reducing delays. Claims managers do not need to access these materials where they are, in large part, already available or locally accessible to

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[49] Transcript for 07/05/2025; 171/16-171/17 (Nick Thomas-Symonds)

[50] Transcript for 08/05/2025; 69/10-21; (Sir Robert Francis); Transcript for 08/05/2025; 72/18-73/12 (David Foley)

[51] See WITN7759001_0019-0020 at paras 68-72 (Benjamin Harrison) as an example of how much more efficiency early involvement of solicitors in the process can create, as opposed to information already available being sought out by claims managers from third parties

solicitors.[52] It is imperative that applicants are made aware of the right to legal representation at the outset of their involvement with the process, in particular from those firms of recognised legal representatives who were instructed in the inquiry and whose experience and expertise in handling matters related to infected blood is beyond doubt.

Advocacy

2.79 Support for the charitable bodies needs to be increased and guaranteed. That is not the same as and should not be conflated with the need for proper legal support but it is equally valuable and also necessary. In the evidence heard by the Inquiry, the Paymaster General stated that he had always pushed for increased funding for the charitable bodies listed in recommendation of the Inquiry report for the reasons the recommendation was made, including their "extraordinary eQorts".[53] Sir Robert Francis made clear that he values the assistance the IBCA received from these bodies.[54]

2.80 In her evidence, Kate Burt of the Haemophilia Society revealed that the Society has been offered £500,000 by the UK Government, a sum which she considered to be insufficient based on the likely need for support for applicants to the IBCA and the planned duration of the scheme.[55] This had been pushed through based, at least in part, on the impending Inquiry hearings.[56] No such offer has been made to the Scottish Infected Blood Forum or Haemophilia Scotland. It was made clear in the evidence of the Chair of Haemophilia Northern Ireland that his experience had been that finding money from the devolved Northern Irish health budget had proven difficult due to other pressing financial considerations and priorities.[57] The Paymaster

[52] WITN7760001, paragraph 62 (Patrick McGuire)
[53] Transcript for 07/05/2025; 174/20-175/1 (Nick Thomas-Symonds)
[54] Transcript for 08/05/2025; 97/9-17 (Sir Robert Francis)
[55] Transcript for 07/05/2025; 67/4-21 (Kate Burt)
[56] Transcript for 07/05/2025; 173/10-16 (Nick Thomas-Symonds)
[57] Transcript for 07/05/2025; 71/21-73/13 (Nigel Hamilton)

General provided unspecific evidence about the arrangements for this Recommendation to be implemented in the devolved nations, in particular referring to the possibility that some announcement might be made in this regard in his updated to Parliament on the implementation of the recommendations of the Inquiry on 20 May 2025. Importantly, he accepted that this was a unique situation as the scandal (by which he appears to have meant the infections) had happened before devolution.[58] The consequence of these circumstances, in our submission, gives rise to the clear need for a further recommendation to be made by the Inquiry that funding at specified levels of at least £100,000 for each of the Haemophilia Scotland and the Scottish Infected Blood Forum be made now for the reasons specified under recommendation 10, with further provision for further funding to be paid by the UK Government (and not the Scottish Government) to each of these organisations on an annual basis, at least for the lifetime of IBCA and backdated to May 2024 to recognise the evidence of the increase workload imposed on these bodies since the Scheme was announced by the UK Government. In our submission, this is consistent with the need for more funding than has been made available to the Haemophilia Society to be made available, the responsibility of the UK Government for the consequences of the disaster and the need for the Inquiry to be specific in its recommendations so that the UK Government has no basis for avoiding their immediate implementation.

3. Priority according to which cases should be processed

3.1 The evidence collated and heard by the Inquiry demonstrates clearly that there was considerable and justifiable frustration amongst the infected and affected community regarding the time which is being taken for claims to be processed. Though it was the Paymaster General's evidence that the dates which had

[58] Transcript for 07/05/2025; 188/3-25 (Nick Thomas-Symonds)

been released by which different categories of claims would be processed were backstops, not targets, closer scrutiny of what he had to say shows that even the 2029 backstop for the affected claims was not in fact the final date by which such claims might be processed as he referred to the "bulk" of claims being processed by that time.[59]

3.2 It was clearly expressed in the evidence of Mr Quinault that some priority needed to be imposed and that some would need to come later in the planning than others. In our submission, though this is an inevitable fact, more resourcing being allocated more quickly, along with legal representatives being involved at an early stage in claims will make the process move forward more speedily for everyone. A more nuanced approach to prioritisation of claims could usefully incorporate of the following features:

(a) In general, we consider it important that people are able to become registered in the system, whether their claims are able to be processed and offers made now or not. The system whereby individuals are invited to make an application to the system has not worked. It has inevitably given rise to some claimants becoming frustrated and even raising concerns that the system will not get to their claims, particularly amongst the affected, whose claims do not currently transmit to their estates. The IBCA should issue an application form to all who request it so they can start operating as intended under the Regulations.[60] As is set out elsewhere in this submission, it is reasonably anticipated that allowing claimants to use legal representation at the start of their applications will speed the early parts of the process up, based on existing legal representatives having ready access to many of the materials necessary to get the application going. This should free up claims managers to enable them to docus on getting claims registered in the system, as opposed to spending time gathering materials which are already available on many cases to legal representatives. This should allow a large-scale administrative effort to be undertaken to get people into the system. This will allow

[59] Transcript for 07/05/25; 136/23-138/20 (Nick Thomas-Symonds)
[60] As per Regulation 65 of the 2025 Regulations

applicants to feel that they are part of the system and go some way to allaying concerns about being disconnected from the process. As pointed out above, we submit that work could be sub-contracted to the IBSSs to enable registration to proceed more efficiently;

(b) Priority being given to those who have so far been denied any form of compensation or support payment should be factored into the Scheme, at least to the point of registering them so that they can access interim payments;

(c) Though a decision appears to have been taken in principle to deal with living infected claims before others, a clearer priority for those who are elderly and/ or in poor health. In order to avoid the need for considerable assessment of the circumstances of individuals (consistent with the tariff based approach to the Scheme) priority should be given to those who are infected or affected and 70 or over and those who are able to assert that they have a life expectancy of 1 year or less (whose position should be assumed on the basis of their assertion that that is the case);

(d) Beyond those priority cases, a greater priority should be accorded the infected deceased (a term which is preferred to the term "estate claims"). Concern has been expressed that infected deceased claims are frequently conflated with the affected claims. This will have the advantage of providing recognition for the claims of those who were infected and who happened to have died as well as providing some level of priority for affected claims, the affected currently being the last whose claims are planned to be processed. Though the claims of the affected themselves would still have to wait, this approach would result in some money being paid to the family of a deceased person before the final claims are handled. This would provide some level of financial recognition which may be available to the affected (many of whom have never received any payments under support schemes) and allay any financial hardship. Infected deceased claims should be able to be processed alongside the living infected claims; and

(e) Processing applications of the affected at the same time associated infected cases would make logical sense and would go some way towards addressing the concerns of affected people who would otherwise require to wait until the end of the process. Though affected claims are distinct and are vested in the affected

person themselves, some of the same material will have to be analysed in processing both the infected and the affected claims, such as evidence relating to the infection and its progression in the infected person. It would make administrative sense to handle associated claims like this together so that the case can be assessed as opposed to processing the associated claims separately.

4. Conclusions and proposed solutions

4.1 We submit that there is a clear basis in the evidence available to the Inquiry that the UK Government's approach to the IBCS (a) does not accord with the findings and recommendations of the Inquiry (despite consistent assertions by the UK Government that it does) and (b) continues to cause and compound significant and unnecessary harm to the infected an affected community which the compensation scheme recommended by the Inquiry was designed to seek to redress. The solution to this is for the Inquiry to write another report, highlighting aspects of its findings and recommendations which have not been followed so that there is a clear public record of where things have gone wrong and how matters need to be remedied.

4.2 What is more, as we predicted in our earlier submissions to the Inquiry[61], the UK Government cannot be and will not be trusted by the infected and affected community to deliver the compensation scheme which was recommended by the Inquiry. By way of contrast, the evidence heard by the Inquiry shows that those individuals (for whose benefit the compensation scheme ought to be designed) **do** have trust in the Inquiry. It was our contention in our previous submissions that that would be the case at this point, in light of evidence heard by the Inquiry as to the UK Government's response to its second interim report. Scepticism about the likelihood that the UK Government would implement its recommendations, we suspect, was the principal reason why the Inquiry kept itself open and has held further hearings. That scepticism was well founded.

[61] SUBS0000064_1240 *et seq*

4.3 Thus, we reiterate our principal contention that the Inquiry cannot leave it to the UK Government to set the principles and tariffs which lie behind the compensation scheme. It is the Inquiry which has heard the and understands not only the evidence which underpins the Inquiry's recommendations on the technical aspects of the compensation scheme which it recommended in its second interim report but also the whole gamut of the evidence which gave rise to the moral case for its existence. It is only the Inquiry which is in a position to set what fair compensation is and be trusted by the infected and affected community to do so. This inevitably must involve recommendations which seek to re-shape the current Scheme and raise the amounts of compensation to be awarded, as set out in this submission.

4.4 Much like the Inquiry itself, there is a need for the UK government to take a backward looking and forward-looking approach to the current significant issues with the IBCS. The backward-looking requirement involves reflection on the issues which have been faced, with actual honesty. It needs to ask itself whether its commitments to the moral imperative for compensation and its commitment to honesty and transparency have been respected in the way it has gone about things. It needs to look again at the Inquiry's evidence and conclusions. Having done so, it needs to look forward and commit to actual solutions. It needs to involve the infected and affected community and their representatives who know and can assist in both functions.

4.5 We make the following proposals as to what recommendations should be made by the Inquiry to seek to resolve the issues which have been faced:

<u>Reset</u>

1. The Inquiry must document with care the events which have, since May 2024 resulted in the need for the inquiry to seek additional evidence and hold additional hearings on the IBCS (as set out above). It must document the harrowing effects which this has had on the infected and affected community.

2. The Inquiry must recommend an immediate reset of the UK Government's and IBCA's approach to the compensation Scheme and its engagement with the infected and affected community it is designed to serve.
3. This must involve better and effective engagement with the infected and affected community as the Inquiry had intended – the user advisory board to IBCA with a broad range of experience of different types of infection and experience and from different parts of the country must be set up, with rights to speak at the IBCA Board; the Inquiry must recommend that both the UK Government and IBCA commit to providing clear written explanations of how engagement with the community have been taken into account in decision-making.

Efficiency and priority

4. The work of IBCA must be financially and operationally prioritised by the UK Government, consistent with its ostensible commitment to the moral obligation to pay compensation to the infected and affected community which was based, in part, on the failings of the State to recognise that obligation over decades. Further years of delay must be stated to be unacceptable against that background.
5. Applicants must be invited to apply to get themselves into the system – they should be provided with updates a to progress. The involvement of legal representatives will allow claims to processed into the system more quickly. In addition, IBCA should sub-contract out work to IBSS staff to enable progress to be made with registering cases and to allow IBCA to continue to process cases more quickly.
6. Priority must be given to those in the greatest need and the most elderly, as well greater priority being accorded to the claims of the infected deceased, as is set out above.
7. In addition, priority should be given to the initial processing of the claims of living infected people who have never before received any support payments, including

those who are suffering from HBV. Clarity should be recommended around the power of IBCA to make awards of interim compensation in the sum of £310,000 to such individuals.

8. Associated claims (for example for infected individuals and their spouses) should be processed together.

Independence

9. The IBCA must be a truly independent body which is not effectively controlled by the Cabinet Office or other arm of UK Government, as it has been. It must be enabled immediately to recruit its own staff who are not from the civil service.

Recasting of the Regulations

10. Although we do not go as far as to seek that the Inquiry recommend a complete restart of the IBCA system, the Regulations which underpin the current Scheme must be recast, as set out above. This includes the following:

(a) The entire Regulations should be recast with greater simplicity and transparency in mind;

(b) The infection windows should be removed as being inconsistent with the evidence and based on a false premise about the State's moral responsibility for the Scheme;

(c) The HCV severity bands are recast by the Inquiry to reflect the full extent of the losses associated with typical infection and the need for a degree of self-assessment in their application;

(d) The Inquiry should review the levels of award being offered to children of infected parents;

(e) The supplementary route should be recast as it was originally intended, with the restrictive severe health conditions being removed, an additional injury award added and a process for calculation of exceptional financial and care awards to be based on evidence beyond the ability to produce actual earnings information. It should also cater for exceptional affected claims;

(f) The unethical research award, which should be made by way of uplift on an entire compensation award for all applicants to recognise the actual effects of non consensual testing, with greater uplifts for those who were treated for bleeding disorders as children or who were treated at centres which are deemed to have involved research;

(g) The formulae under regulation 7 should be removed and be replaced with a more simple method of undertaking past financial loss calculation;

(h) The deeming provisions under regulation 20 and the way they are applied to the calculation of past financial losses should be applied to the date of the diagnosis and not worked out from the date of the application;

(i) The percentage reductions on past financial loss should be removed; and

(j) The Regulations should be altered so as to allow affected claims to transmit to their estate when they die or at least that claims which have been registered should so transmit.

11. It is essential that the changes to the Scheme which it is proposed be recommended at this stage by the Inquiry should not give rise to significant delay in claims being processed. It will be necessary for the Regulations to be further updated and improved, which will inevitably take some time. This should not stop the work of the IBCA progressing as had been planned under the current Regulations. In the meantime, we suggest that the claims made under the current Regulations should be processed but any offers made and accepted should be treated as interim offers, with a re-assessment of claims being done at a later stage when new Regulations are enacted.

12. Our preference would be for the Inquiry to make recommendations as to the precise changes, both to the mechanics of the Scheme and as regards higher

levels of payments which must be made in areas listed above be made by the Inquiry in its further report (with any further consultation on the details which is deemed necessary). This claim is based on the view of those on whose behalf it has been drafted (both since May 2024 and for the many decades before that date) that the UK Government can simply not be trusted to implement the carefully set out and to do so based on the body of evidence which was heard and accepted by the Inquiry and on the basis of which the recommendation was made for a compensation scheme to be created.

13. If this is not the Inquiry's favoured approach, it must reiterate the need for meaningful and transparent consultation with the legal representatives of the infected and affected community and for submissions to be made to a body of which they are part as to the changes which need to be made to make the Scheme work more equitably and logically, with appropriate tariffs for all aspects of the loss which the inquiry has identified.

The operation of IBCA

14. The Inquiry should recommend that the role and qualifications of clinical assessors need to be overhauled.

15. In addition, a clear, system fully funded by the UK Government for the legal representation of applicants to IBCA must be recommended.

Accountability

16. Whatever route is taken by the Inquiry, it must keep its doors open to the future need to intervene as it has done to ensure that the compensation Scheme is altered as it has recommended. It should recommend that clear, regular communications are issued by the UK Government and IBCA, making it clear what

action has been taken in response to representations. Made on behalf of applicants as to the changes which are required to the Scheme and why, as is set out above. Immediate oversight of the UK Government's and IBCA's actions as regards the compensation scheme and the necessary changes is needed by a parliamentary committee.

Advocacy

17. Funding for the considerable additional requirements of charitable bodies in the administration of the ICBS must be made to Haemophilia Scotland and the Scottish infected Blood Forum, backdated to May 2024, in addition to funding for advocacy undertaken by those bodies more generally.

James T Dawson KC

Heather Arlidge

23 May 2025