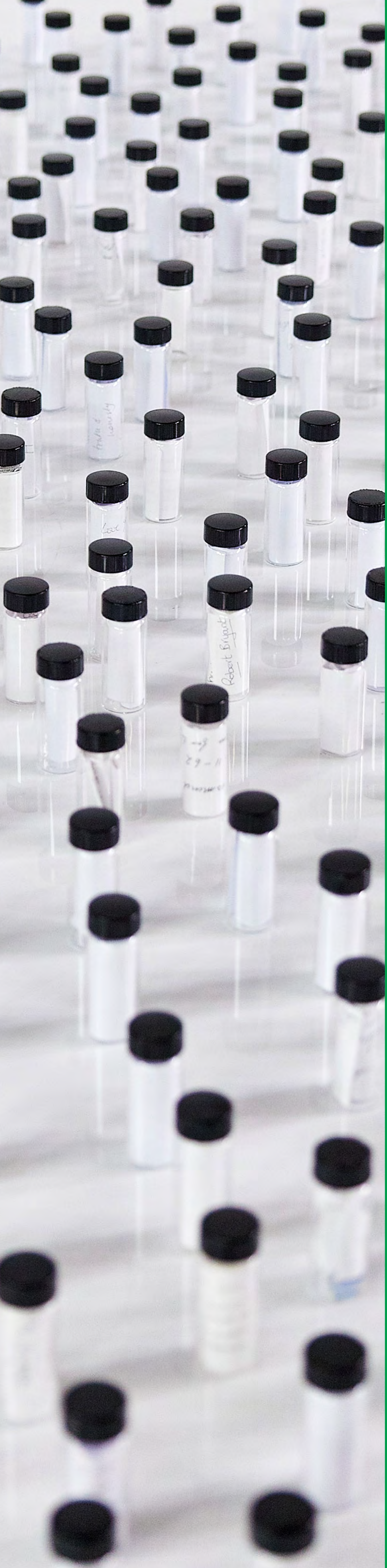

Infected Blood Inquiry

Additional Report
on Compensation

Response of Government and the Infected Blood Compensation Authority

- Overview
- Design of the Compensation Scheme
- Operation of the Compensation Scheme
- HIV transmitted before 1982
- Hepatitis
- Specific concerns
- People affected
- Bereavement after 31 March 2025
- Recommendations
- Concluding remarks

9 July 2025
HC 1167

Infected Blood Inquiry

Additional Report

on Compensation

Presented to Parliament pursuant to section 26 of the
Inquiries Act 2005.

9 July 2025
HC 1167

This publication is available at www.gov.uk/official-documents.

Any enquiries regarding this publication should be sent to us at contact@infectedbloodinquiry.org.uk.

ISBN 978-1-5286-5876-8
E03396011 06/25

Printed on paper containing 40% recycled fibre content minimum.

Printed in the UK by HH Associates Ltd. on behalf of the Controller of His Majesty's Stationery Office.

Contents

1 Overview

On 20 May 2024 – the day on which the Inquiry Report was published – the then Prime Minister Rishi Sunak promised that the Government "*will pay comprehensive compensation to those infected and affected by this scandal … Whatever it costs to deliver the scheme, we will pay it.*"

The Leader of the Opposition (now Prime Minister) Sir Keir Starmer acknowledged in response:

> "*this is an injustice that has spanned across Governments on an unprecedented stage … I want to acknowledge to every single person who has suffered that, in addition to all the other failings, politics itself failed you … suffering was caused by wrongdoing, delay and systemic failure across the board, accompanied by institutional defensiveness … any apology today must be accompanied by action, so I welcome the Prime Minister's confirmation that compensation will now be paid … we will work with him to get that done swiftly, because – make no mistake – the victims in this scandal have suffered unspeakably. Thousands of people have died; they continue to die every week. Lives completely shattered; evidence wilfully destroyed; victims marginalised; people watching their loved ones die; children used as objects of research – on and on it goes. The pain is barely conceivable.*"[1]

Within days the relief and vindication that many people infected and affected felt on 20 May 2024 had turned to anxiety, confusion and distress following the publication by the Government of information about its proposed compensation scheme.[2]

In autumn 2024, the Inquiry began to receive increasingly concerned communications from individuals, organisations and legal representatives regarding the compensation scheme – how it had been designed without the participation of people infected and affected, the way in which the scheme was structured and being operated and the length of time it was taking for the Infected Blood Compensation Authority (IBCA) to make compensation payments. Those communications, which have continued to the present day, contained expressions of distress, anger, frustration and despair.

> "*we were looking forward to being able to start the process of closure and healing and attaining a level of peace whereby we could start to move on with our lives. Instead, we are left feeling that age and illness are catching up with us; there is no rest, there is no peace …*"[3]

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[1] Hansard Statements by the Prime Minister and Leader of the Opposition 20 May 2024 pp1-3 RLIT0002476

[2] See the section *Elation to despair* within the Counsel Presentation: Evidence Concerning Compensation 29 April 2025 pp3-4 INQY0000464

[3] Second Written Statement of Glenn Wilkinson para 10 WITN2050115

> "*It feels as if we are waiting to die, in limbo, unable to make any progress in our lives and fearing as our health declines we may not ever get the compensation awards we deserve.*"[4]

People have described "*a situation where trust and confidence, both in Government and, unfortunately, to a certain extent in IBCA, has collapsed … It's a lack of trust and confidence.*"[5]

This Additional Report has been written following the hearings which took place on 7-8 May 2025 and following careful consideration of the oral evidence and all of the statements, documents, communications and submissions that the Inquiry has received. Announcing those hearings I explained that:

> "*The decision to hold hearings has not been taken lightly. It reflects the gravity of the concerns expressed consistently and repeatedly to the Inquiry. These merit exploration in public. People infected and affected do not have time on their side. Our goal is to be constructive and to identify what actions can be taken by the Government and Infected Blood Compensation Authority to address the concerns, and help them gain the trust of those who have had to wait many decades for recognition and compensation.*"[6]

Much of this Additional Report therefore addresses issues relating to the current operation of the infected blood compensation scheme, and proposals for changes to the scheme which have been made by and on behalf of people infected and affected.

However, written submissions received by the Inquiry on behalf of people infected and affected have also asked the Inquiry (as its Terms of Reference permit) to examine the way in which the scheme, about which so many concerns have been expressed, has come about. For example, the submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland), suggest that:

> "*it is important that the Inquiry documents clearly the failures associated with the way in which* [the scheme] *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 …*"[7]

The submissions on behalf of the core participants represented by Leigh Day make a similar point. Referring to "*the delays, lack of consultation, and absence of transparency that characterised the establishment of the Scheme*", they add that "*we trust the Inquiry will fully assess the background when reporting, in order that the course can be corrected.*"[8]

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[4] Fifth Written Statement of Carol Grayson para 16 WITN1055207

[5] William Wright Transcript 7 May 2025 p12 INQY1000283

[6] Infected Blood Inquiry news story 9 April 2025 INQY0000466

[7] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.1 SUBS0000084

[8] Written Submissions on behalf of the core participants represented by Leigh Day paras 4-5 SUBS0000088

Doing so has a purpose beyond giving a definitive account of the facts. Unless we properly understand the history, some of the lessons of the past will be ignored and it is clear that, without appreciating the truth, reconciliation becomes more difficult.

Accordingly, this Additional Report begins with an examination of how the compensation scheme as presently established has come about (see **Chapter 2 *Design of the Compensation Scheme***). It considers in particular the lack of involvement of people infected and affected in the design of the scheme and the role of the Expert Group.

Chapter 3 *Operation of the Compensation Scheme* explores the statutory framework for the Infected Blood Compensation Authority (IBCA) and the relationship between IBCA and the Cabinet Office. It then turns to consider the approach of IBCA to involving people infected and affected, the question of transparency in IBCA's operations, the role of clinical assessors, the involvement of legal representatives, the reasons for IBCA's slow start and the process for internal review of IBCA's decisions.

Scrutiny of the compensation scheme has thrown up new issues about the way in which the Infected Blood Compensation Scheme Regulations 2025 work. **Chapter 4 *HIV transmitted before 1982*** looks at the exclusion of people infected with HIV before 1982 from the compensation scheme and concludes that it is both illogical and unjust.

Multiple concerns have been raised about the treatment of Hepatitis within the compensation scheme. **Chapter 5 *Hepatitis*** addresses three issues which have arisen: (1) why the scheme does not include provisions reflecting the Special Category Mechanism (and its equivalents under the other national schemes); (2) whether sufficient consideration has been given to the effects and consequences of interferon treatment and to the extra-hepatic manifestations of Hepatitis; and (3) whether the legislative definition of Level 3 (cirrhosis) has been correctly understood and applied in practice.

Chapter 6 *Specific Concerns* considers a number of issues which arise out of the way in which specific provisions within the Infected Blood Compensation Scheme Regulations 2025 have been drafted and asks whether there are adjustments to the scheme that should be made to correct obvious unfairness and/or to ensure that the detail of the scheme matches up to its intent. These issues are: (1) the scheme's treatment of severe psychological harm; (2) the way in which the scheme treats the date of effective treatment for Hepatitis; (3) the deeming provisions regarding Hepatitis severity levels; (4) the requirement for evidence to be provided of the date of diagnosis for Hepatitis; (5) aspects of the way in which the scheme calculates financial and care losses; and (6) the unethical research award.

Much unhappiness has been expressed about the scheme's treatment of people affected. This is considered in **Chapter 7 *People affected***.

The position of people bereaved after 31 March 2025 who will have no entitlement to ongoing support payments (in contrast to the position of people bereaved on or before 31 March) is examined in **Chapter 8 *Bereavement after 31 March 2025***.

Finally, the Report details the recommendations which the Inquiry is making to IBCA and the Government (**Chapter 9 *Recommendations***) and sets out some concluding observations (**Chapter 10**).

Andrew Evans, who was infected aged five with HIV and Hepatitis C and chairs the Tainted Blood campaign group which has around 2,100 members, wrote:

> "*We are where we are, however aggrieved we may feel about this, and speed of implementation has never been more urgent.*
>
> *Having said that, we would like to see that there is a path ahead whereby decisions on compensation policy for this scandal will be constantly revisited, that inadequacies could be remedied, and that we as victims and supporters of victims will have an active part in that. This does not mean that the scheme as it stands should not go ahead and continue making payments to victims, but rather that the development of the scheme at a policy level should be an ongoing process, and that the effects of any changes made to correct the scheme could be retroactively applied to those who have already claimed.*"[9]

There can be no doubt that the Government has done right in ways which powerfully signal its intent. It has introduced a compensation scheme, set up and financed a body whose sole focus is delivering that compensation, and reserved a considerable allocation of funds for the purpose. It has helped IBCA to be in a position to say that by the end of this year they expect to have begun claims for all living infected people registered with support schemes. However, there is still more to be done to ensure that the detail and operation of the scheme matches up to its intent.

Nick Thomas-Symonds, as Minister for the Cabinet Office, wrote in February this year:

> "*The infected blood community must sit at the heart of the Infected Blood Compensation Scheme. The Infected Blood Inquiry and Sir Robert Francis reflected on the experience of the community to inform their recommendations, and these recommendations continue to form the basis of the Scheme …*"[10]

It is that community which has, collectively, raised concerns about important aspects of the scheme. It is that community which points to modifications which, if made, would reduce its collective feeling that some people are unfairly disadvantaged. It is that community which has heard the Minister both acknowledge in his opening statement to the Inquiry in May: "*I know many people before me will have suffered unimaginably because of this scandal*" and commit to being open to making changes to the scheme itself provided these did not cause even greater delay for justice. Honouring that commitment could represent the start of the "*path ahead*" that Andrew Evans identified.

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[9] Fourth Written Statement of Andrew Evans paras 18-19 WITN1213015

[10] Introduction to Expert Group Addendum Report February 2025 p4 WITN7762015

2 Design of the Compensation Scheme

Recent history: a recap

It was known and understood by Government in 2017 when the long overdue Inquiry was announced that the Inquiry might well recommend substantial compensation.[11]

No action was taken by Government between 2017 and mid-2020 with regards to compensation.

On 13 July 2020 the then Paymaster General, Penny Mordaunt, wrote to the Chancellor of the Exchequer, Rishi Sunak, explaining that "*I believe it to be inevitable that the Government will need to provide substantial compensation … I believe we should begin preparing for this now*".[12]

She wrote again on 21 September 2020 that "*I firmly believe that we should begin preparing for this now … I cannot stress enough the urgency of taking long overdue action on financial support and compensation.*"[13]

On 25 March 2021 she announced the Government's intention to commission an independent study to advise on a compensation framework,[14] and on 20 May 2021 the appointment of Sir Robert Francis QC;[15] his study would "*provide the Government with advice and recommendations on a potential compensation framework.*"[16]

Sir Robert's Infected Blood Compensation Framework Study ("the Compensation Study") was in due course delivered to the Government on 14 March 2022. It was published by the Government on 7 June 2022.[17] The Government did not publish any response to the Compensation Study, despite having promised to do so, and instead said that the Government would be ready to respond to the Inquiry's recommendations.[18]

On 29 July 2022 the Inquiry published its first Interim Report, recommending interim payments to people who were infected and to bereaved partners.[19] The Government accepted that recommendation promptly on 17 August 2022.[20]

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[11] See Infected Blood Inquiry Report 20 May 2024 Volume 7 pp177-178 INQY0001007

[12] Letter from Penny Mordaunt to Rishi Sunak 13 July 2020 p2 EIBS0000706

[13] Letter from Penny Mordaunt to Rishi Sunak 21 September 2020 EIBS0000705

[14] Hansard Statement by the Paymaster General 25 March 2021 WITN4066017

[15] Now KC.

[16] Press release Appointment of Sir Robert Francis QC to undertake the infected blood compensation framework study 20 May 2021 p2 RLIT0002057

[17] Infected Blood Compensation Study 14 March 2022 RLIT0001129

[18] Infected Blood Inquiry Report 20 May 2024 Volume 7 pp265-6 INQY0001007

[19] Infected Blood Inquiry First Interim Report 29 July 2022 INQY0000367

[20] Press Release Infected Blood victims to receive £100,000 interim compensation payment 17 August 2022 RLIT0002086

On 5 September 2022 the Paymaster General (now Michael Ellis) reiterated that the Government would not respond to the Compensation Study until the final report of the Inquiry was published.[21]

It was not until 30 November 2022 that senior officials across government met for the first time to consider compensation,[22] and a Small Ministerial Group established by the Paymaster General (now Jeremy Quin) met for the first time to discuss the issue on 22 February 2023.[23]

The moral case for compensation was formally accepted by the Government on 15 December 2022. The Government stated, however, that "*Our comprehensive response must await the final report of the infected blood inquiry*".[24]

On 5 April 2023 the Inquiry published its Second Interim Report, which contained its full recommendations on compensation.[25]

The Government's initial response was communicated by Jeremy Quin in a statement to Parliament on 19 April 2023. The Government was, he said, "*working at pace across all relevant Departments to consider the recommendations as outlined in this latest report and to ensure that we are best placed to respond to the Inquiry's final report.*"[26]

In late July 2023 the Inquiry held further hearings at which evidence as to the Government's position was heard from the Paymaster General (Jeremy Quin), the Chancellor of the Exchequer (Jeremy Hunt) and the Prime Minister (Rishi Sunak).

On 4 December 2023 Dame Diana Johnson tabled an amendment to the Victims and Prisoners Bill requiring the Government to establish a body to administer a compensation scheme for victims of the infected blood scandal within three months of the passing of the Act (an amendment which was opposed by the Government). During the debate, the Government announced the intention to bring forward its own amendments when the Bill reached the Lords.[27]

On 18 December 2023 the Paymaster General (now John Glen) told Parliament that:

> "*It is now a year on from the Government's acceptance of the moral case for compensation, and I understand the calls for urgency. I know that, from many of those infected and affected, there is anger and frustration with the Government's response so far. The Inquiry's recommendations are not without complexity, and*

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[21] Hansard Statement by the Paymaster General 5 September 2022 p2 RLIT0002094

[22] Second Written Statement of Jeremy Quin para 8 WITN7526002

[23] Second Written Statement of Jeremy Quin para 9 WITN7526002

[24] Hansard Statement by the Paymaster General 15 December 2022 p2 COLL0000022

[25] Infected Blood Inquiry Second Interim Report 5 April 2023 INQY0000453

[26] Hansard Statement by the Paymaster General 19 April 2023 p2 RLIT0002126

[27] Edward Argar, then Minister of State at the Ministry of Justice, told the House of Commons that "*when the Bill reaches the Lords, we will bring forward our own amendment, which will put in place the necessary legislative framework and timescales for a delivery body for compensation for the victims of infected blood to be established, in line with the overall objectives set out in* [Diana Johnson's] *new clause.*" Hansard House of Commons debate on the Victims and Prisoners Bill 4 December 2023 p57, pp66-67 RLIT0002349

> *it would be inappropriate for the Government to prejudge the findings of the final report. For these reasons, the Government are not yet in a position to share any final decisions on compensation.*"

He added that the Government was "*urgently appointing clinical, legal and social care experts to advise the Cabinet Office on detailed technical considerations early in the new year, which will ensure that the Government have the relevant expertise to make informed choices in responding to the Inquiry's recommendations on compensation.*"[28] This was the first public reference to the Expert Group chaired by Professor Sir Jonathan Montgomery, a subject which this Additional Report considers further below.

In the Inquiry Report published on 20 May 2024, I made the following observations and conclusions:[29]

(a) The Government did not do what it said it would: to publish its response to the Compensation Framework Study alongside the study itself and in advance of Sir Robert's evidence to the Inquiry.

(b) The Government then failed to publish its response after Sir Robert's evidence, despite saying that it would "*act as expeditiously as possible after that.*"

(c) The Government has not yet (as at today) published any response to the Compensation Framework Study.

(d) Little appears to have been done before late 2022. The fact that the first cross-government meeting of senior officials took place in November 2022, that it was only decided in early 2023 to establish a DHSC team to undertake costs analysis, that the Small Ministerial Group met for the first time on 22 February 2023, and that the first ministerial meeting involving the devolved administrations was not until June 2023 have the appearance of working at a sluggish pace.

(e) The Government said it was planning to be ready in response to compensation recommendations that it expected to arrive in mid and then autumn 2023. On that timescale, its work should now be complete.

(f) Such evidence as there is suggests that this is not the case and that key decisions may still remain to be made.

(g) At several stages Government has said that it would update Parliament with as much detail as it could as work progressed. It is a matter of regret that it has found little to report.

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[28] Hansard Statement by the Paymaster General 18 December 2023 pp 1-2 RLIT0002341

[29] What follows is an extract from Volume 7 of the Inquiry Report.

The effect of what has happened is that the Inquiry's own consideration of compensation has not been able to be informed by the Government's response to the Compensation Framework Study, that the Government's response has (thus far) escaped the scrutiny of the Inquiry; and that those infected and affected have felt a lack of transparency and openness characteristic of what they have had to face, and have been fighting, for nearly half a century.

The rationale of waiting for this Report, as explained to the Inquiry, begs for a better explanation. This is not a case in which the Government is expecting a report that says everything was done as it should have been. Jeremy Quin's expectation as at 22 June 2023 was that the full report would put the compensation proposals "*into further and – I fear in many ways – deeply upsetting context.*" He confirmed a month later in his oral evidence his expectation that the final report "*will unveil very, very significant issues that happened over many decades and should never have happened.*" Penny Mordaunt recognised in Parliament in October 2023 that people have suffered "*layer upon layer of injustice*". The Prime Minister has acknowledged that what has happened "*has been an appalling scandal … thousands of people … have suffered for decades, and they have suffered a layer of injustices at that … this is not just about historic wrongs, people are suffering and being impacted today.*"

Despite this, and the Government's acceptance of the moral case for compensation in December 2022, the Government has insisted upon waiting for this Report, despite knowing that the Inquiry's Second Interim Report contains its full recommendations on compensation.

Jeremy Quin has suggested the final report "*will enable the Government to see those recommendations in their full context*" and that "*Being able to put the Government's response into the context of those findings is a useful and helpful thing to do in justifying our actions*". Jeremy Hunt expressed the view that it was "*responsible and right to the taxpayers, who are funding this, for Government ministers to see the full context of the horrific scandal that this was, before we make the final decision as to how compensation will work.*" But when the Government knows, as it clearly does, that what happened was a terrible injustice, that people deserve redress, and that lack of redress perpetuates the injustice, then to delay, and thus deny, justice in order to await the "*full context*" seems hard to justify.

The Prime Minister's explanation was that it was "*long-standing convention and precedent and advice*" to wait for the conclusion of the Inquiry and that it was normal "*not to make final decisions until an Inquiry has finished.*" Whilst that may well be the usual course – and will reflect the fact that inquiries do not always make interim reports, although they are expressly empowered to do so under the Inquiries Act – the Government's actions in relation to the Post Office Horizon scandal makes plain that decisive, even bold, commitments can be made in advance of an Inquiry's final report.

In the exceptional present context, given the acceptance of moral responsibility, the known urgency in light of passing time, and the vulnerability of those infected and affected (and with people continuing to die without redress), let alone the fact that nearly two years ago now interim payments were made to some of those involved, reliance on "*convention*" and "*precedent*" does not provide a sufficient justification.

Back in November 2022, Jeremy Quin told the Inquiry that work was continuing across government "*so that Government can respond swiftly **to any recommendations relating to compensation** in the Inquiry's final report.*" In other words, the rationale of waiting for the final report was to see what recommendations the Inquiry made regarding compensation. That rationale fell away once the Second Interim Report was published.

Three former health secretaries – Jeremy Hunt, Matt Hancock and Andy Burnham – wrote to the (then) Prime Minister on 3 August 2022, following the Inquiry's First Interim Report, to this effect:

> "*To refuse to do so* [ie to make interim payments as recommended by the Inquiry] *would simply continue the injustice thus far handed out by the state to a group of innocent victims condemned to years of suffering and neglect.*
>
> *Any delay to such payments, for instance by arguing that we need to wait for the inquiry to finish, for a new Prime Minister, or for Parliament to return, will sadly almost certainly see more of the victims die before they see justice. Already more than 400 people have died since the inquiry started. With some estimating that one infected person is dying every four days waiting until even the end of the year when the Inquiry hearings are concluded would mean another 40 people would die. That number would be likely to be above 100 if the government waits until the inquiry has reported in full. This is simply unacceptable and will cause yet more harm to a group of exceptionally vulnerable people.*"

These words are as true now as they were then.

In May 2023 the Leader of the House of Commons, Penny Mordaunt, said this:

> "*I have had the privilege of meeting many of those who were infected and affected by that appalling scandal, and I went to hear some of the evidence that they gave at the inquiry. It may fall to us in this place, on our shift, to put that right, but we must put it right. There is not just the original injustice that was done to those people, many of whom were children at the time, but the further layers of injustice that have happened with regard to their financial resilience, as many of them lost their homes and were not able to work, facing the appalling stigma and hardship that came with that. We have to put that right.*"

If the acceptance of a moral case for compensation is not followed by action in providing compensation then the Government is not "*putting it right*".

As the above narrative demonstrates, there have been ample opportunities – and invitations – for the Government to explain what it is doing. It has chosen not to give detail. In his oral evidence to the Inquiry, Lord Jonathan Evans, then chair of the Committee on Standards in Public Life, observed that "*it's central to the whole democratic process that there has to be accountability and that accountability requires openness*". The importance of openness and transparency for those infected and affected, who have been denied truth and justice for decades, should be self-evident. The lack of transparency compounds the harm which has already been inflicted.

It **may** be that a huge amount of work has been undertaken. It **may** be that the Government has decided to accept the recommendations. It **may** be that justice and redress are just around the corner – for those who are still alive. But at the time of writing this Report I have no way of knowing if this is the case. Nor, more importantly, do those infected and affected. That is a serious failing which replicates the wrongs of the past. People whose lives were torn apart by the wrongs done at individual, collective and systemic levels, and by the way in which successive Governments responded to what happened, still have no idea as to the shape, extent or form of any compensation scheme, and no idea, beyond the acceptance of the moral case for compensation and assurances that there will be more to come, of the Government's response either to the Compensation Framework Study or the Second Interim Report.

In 2017 Andy Burnham told Parliament that "*victims now feel that they have been led up to the top of the hill only to be let down once again*" and that the lack of substantial action "*has left people feeling in the wilderness all over again.*" Andy Burnham's call for compensation was seven years ago.

People infected and affected continue to die.

From an early stage of the hearings before the Inquiry it became obvious to any objective onlooker that compensation was likely to be recommended. That was why it was decided to commission Sir Robert to report on what it might cover, and how. The Inquiry said all it had to say by way of recommendation concerning compensation before Easter 2023.

This chapter has been one of the very last I have written, because I had hoped to be able to discuss the Government's response to the Inquiry recommendations concerning compensation, and to be able to report that it had done right by those to whom the recommendations relate. The Government has said it "*accept[s] the will of*

Parliament that arrangements should be put in place to ensure, as far as reasonably practicable, that the victims receive justice as quickly and efficiently as possible." I urge the Government to put these words into action.[30]

The steps taken by the Government between the publication of the Second Interim Report (April 2023) and the publication of the Inquiry Report (May 2024)

Evidence obtained by the Inquiry since the publication of the Inquiry Report in May 2024 has now cast further light on what was being done within Government to consider the question of compensation.

James Quinault is the director general within the Cabinet Office responsible to ministers for work on the Government's response to the Inquiry (including work on designing and drafting legislation for the compensation scheme). He took up this post in June 2023. He has told the Inquiry that in early May 2023 the Government, having considered analysis of the scope and cost of the Inquiry's recommendations, decided to commission further work;[31] that approximately two months later, having considered further analysis of the scope and cost of the recommendations, the Government decided that further interim payments must await decisions on design and eligibility for compensation in a full scheme;[32] that on 28 September 2023 the Government decided that the Cabinet Office should lead on work on the design of a compensation scheme;[33] that on 23 October 2023 the Government decided in principle to appoint medical and legal experts to advise on tariffs and criteria for the compensation scheme;[34] and that on 23 November 2023 the Government decided in principle, subject to approval of a business case, to establish a new delivery body to deliver the scheme.[35]

At no stage prior to the announcement of compensation on 21 May 2024 were people infected and affected involved in the design of the scheme, the eligibility criteria, and what might be appropriate tariffs. This was despite the fact that the decision-making involved determining tariffs which Sir Robert Francis and I had both advised should be informed by the lived experience of the people infected and affected.[36]

James Quinault was asked about this when he gave evidence to the Inquiry:

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[30] Infected Blood Inquiry Report 20 May 2024 Volume 7 pp283-288 INQY0001007

[31] Second Written Statement of James Quinault para 235 WITN7755003

[32] Second Written Statement of James Quinault para 236 WITN7755003

[33] Second Written Statement of James Quinault para 238 WITN7755003

[34] Second Written Statement of James Quinault para 228, para 240 WITN7755003

[35] Second Written Statement of James Quinault para 241 WITN7755003

[36] Infected Blood Compensation Study 14 March 2022 para 2.40, para 2.76, para 9.11 RLIT0001129, Infected Blood Inquiry Second Interim Report 5 April 2023 p23 INQY0000453

> "*Q. Now, who is it who made the decision to have a scheme in which the design and structure of that scheme, the criteria for eligibility and the tariffs, everything which we now see set out in the regulations, was solely determined by Government?*
>
> *A. That decision had already been taken by the time I took up my post* [in June 2023] *and was a decision taken by the Government at the time and ministers – taken in principle at least, and ministers in their statements to Parliament thereafter made clear that they were going to be unlikely to accept the Inquiry's recommendation on that point.*
>
> *Q. So by June 2023, the internal position within Government … the internal position was that ministers, and it's a ministerial decision, had decided that it was going to be, as it were, a Government-created scheme?*
>
> *A. I don't know if they had gone as far as that but they had decided that the scheme would not be administered by a body wholly independent reporting directly to Parliament and not through ministers. That had I think been decided in principle by that point.*"[37]

When the Small Ministerial Group had met in May 2023, they discussed a paper about departmental ownership of the compensation scheme, with the options including the Cabinet Office, Department of Health and Social Care (DHSC), the Ministry of Justice or another department, a parliamentary body or statutory office holder or some hybrid option. The paper recorded:

> "*Legislation can set out the level of autonomy afforded to an ALB.*[38] *The highest level of autonomy would be, as recommended by Sir Brian and Sir Robert, for the ALB* [to] *report directly to Parliament, this could be set out in the legislative obligations of the ALB.*"[39]

The Small Ministerial Group expressed "*concern that an Arms Length Body reporting directly to Parliament, with no Ministerial oversight, would be an open-ended amount of money. This would not allow the Government to ensure fiscal responsibility.*" They asked for work on two options for departmental ownership, sole DHSC ownership and hybrid Cabinet Office and

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[37] James Quinault Transcript 8 May 2025 pp110-111 INQY1000284

[38] Arm's Length Body.

[39] Options for a ministerial decision on Departmental Ownership of an Infected Blood Compensation Scheme 3 May 2023 para 19 CABO0000913. See also para 35: "*Sir Brian Langstaff has put forward a model for an ALB which is truly independent of government. A parliamentary body (e.g. the Independent Parliamentary Standards Authority) or a statutory office holder (e.g. the Commissioner for Public Appointments) could be established through legislation. This body would report directly to Parliament and not have departmental oversight, although Ministers would still be responsible for the system created e.g. to a Parliamentary Committee. The Parliamentary and Health Service Ombudsman (PHSO) may represent an analogy but has no power of redress.*" The perceived advantages of, and barriers to, this option were outlined in paras 36-37 of the paper.

DHSC ownership.[40] At this stage, they did not decide that the Cabinet Office would assume responsibility for the scheme.

A submission to the Minister for the Cabinet Office in October 2023 advised:

> "*We have established with you and* [the Treasury] *that* [the Government] *must hold accountability of the overall design of the scheme and tariff rates, in contrast to the recommendations of Sir Brian Langstaff. Although it would not have the independence of an ALB established by statute, and therefore does not comply with* [Sir Brian Langstaff's] *recommendation on how compensation awards should be set, having an expert committee established may help to demonstrate, at least to some extent, that the compensation scheme has been designed by those with some independence from* [the Government]*, which might enhance the credibility of the scheme with the infected blood community.*"[41]

By way of comment, it is plain that the author of the submission was concerned about the credibility of a proposed scheme with the infected blood community. It is difficult to see how the appointment of an expert group to advise would enhance that credibility, unless its appointment was transparent, the community had some involvement in its formation and there had been meaningful involvement in the issues it was to be asked to help to determine.

The fact that the Inquiry's recommendation regarding the establishment of the scheme was to be rejected plainly made it **more** rather than **less** important that there should be full and frank engagement and consultation with people infected and affected. In practice there was none. Instead, on 22 January 2024 the Expert Group was formally appointed.[42]

On 26 February 2024 the role of the Expert Group was described by Earl Howe, the Deputy Leader of the House of Lords, as "*to enable Ministers to understand certain technical issues and thus enable decisions to be made more quickly.*"[43] He asserted, in relation to the Victims and Prisoners Bill, that the Government was "*eager to avoid more needless delay*" and "*well aware that every passing season sees more suffering, death and bereavement.*"[44]

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[40] Minutes of the Small Ministerial Group on Infected Blood Inquiry 3 May 2023 p6 CABO0000914

[41] The submission went on: "*There is a risk that accepting recommendation 14* [the Inquiry's recommendation for an Arms Length Body] *in full will not provide the Government with proper oversight of the potential fiscal spend incurred by the compensation scheme. We recommend that the expert committee is appointed with a chair who provides advice directly to you* [Minister for the Cabinet Office] *for decision-making purposes, rather than taking independent decisions.*" Submission on Infected Blood Inquiry Response: Expert Advisers 19 October 2023 p2 CABO0000918. The opposition took a similar position. Nick Thomas-Symonds, then Shadow Minister Without Portfolio in the Cabinet Office, urging progress in December 2023, said "*As with any arm's length body, the Government will be responsible for appointing the chair and the members, and setting the budget and the rules for the scheme, including on decision making and accountability.*" Hansard House of Commons debate on the Infected Blood Inquiry: Government Response 18 December 2023 p2 RLIT0002341

[42] First Written Statement of James Quinault para 75 WITN7755001, Second Written Statement of James Quinault para 231 WITN7755003

[43] Hansard House of Lords debate on the Victims and Prisoners Bill 26 February 2024 p15 RLIT0002350

[44] Hansard House of Lords debate on the Victims and Prisoners Bill 26 February 2024 p14 RLIT0002350

In circumstances where the extensive delay was attributable to the Government's failure to act earlier, a desire (finally) to move quickly could not and does not justify the failure of the Government to engage proactively with the victims on the scheme, its structure, its criteria for eligibility and its tariffs. Yet one of the features of the Terms of Reference of the Expert Group was that it was precluded from direct contact with anyone who had been infected or affected.[45]

On 17 April 2024 the Paymaster General wrote to all MPs explaining amendments being tabled to the Bill. He stated that the Government recognised that "*more can, and must, be done to provide reassurance to the people who have been infected and affected by this scandal, and we must provide more transparency as we do this.*" He noted that "*colleagues have also asked for further transparency on the work of the expert group and for that reason I will be publishing the Terms of Reference of the expert group.*" He explained that he would be undertaking meetings with representatives from charities, organisations and support groups "*to personally share the progress the Government is making, reassure the community that we have heard their concerns, and seek inputs on specific issues ahead of the Government response to the Infected Blood Inquiry's recommendations on compensation*". He claimed that the Government "*recognises that time is critical*" and that people "*have already waited too long*".[46]

On 30 April 2024, during the Report Stage in the House of Lords, the Government tabled amendments to the Bill. The explanation from Earl Howe included that:

> "*there is an important principle here around maintaining government accountability … The Government simply must hold responsibility for overseeing the expenditure of taxpayers' money, and it would not be appropriate for the rates of compensation to be set by the chair of the IBCA. Instead, the chair will hold an important role in the delivery of the scheme, making sure that the right people receive the right compensation and ensuring support for those who access it, against the parameters set out in legislation.*"[47]

This was, in effect, the first communication of the decision that the Government would itself design the scheme.

Earl Howe also referred to the importance of IBCA being "*operationally and functionally independent and seen to be so*", adding that "*the way in which we are framing the legislation provides for exactly that.*"[48] Whether this goal has been achieved is considered later in this Additional Report.

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[45] Infected Blood Inquiry Response Expert Group Final Report p5 RLIT0002474

[46] Letter from John Glen to all MPs 17 April 2024 p3 WITN7763004

[47] Hansard House of Lords debate on the Victims and Prisoners Bill 30 April 2024 p41 RLIT0002488

[48] Hansard House of Lords debate on the Victims and Prisoners Bill 30 April 2024 p41 RLIT0002488

In early May 2024 John Glen held meetings with various representatives of community groups.[49] By this time, however, the Expert Group had reported to the Government and the Government had designed the parameters of the compensation scheme – without any participation from people infected and affected.

The Government's response following publication of the Infected Blood Inquiry Report on 20 May 2024

On 20 May 2024, following the publication that day of the Infected Blood Inquiry Report, the Prime Minister told Parliament that "*This is a day of shame for the British state*", referring to a "*decades-long moral failure at the heart of our national life.*" Giving a "*whole-hearted and unequivocal apology for this terrible injustice*", the Prime Minister recognised that "*justice also demands action and accountability*". He made a solemn promise that "*we will pay comprehensive compensation to those infected and those affected by this scandal, accepting the principles recommended by the inquiry, which builds on the work of Sir Robert Francis. Whatever it costs to deliver the scheme, we will pay it.*"[50]

The following day the Paymaster General outlined to Parliament the scheme which the Government proposed. He explained that the scheme would be tariff based and that compensation awards would be made in the categories recommended by the Inquiry ("*with two small refinements*"). He said that over the next few weeks Sir Robert Francis would seek views from the infected blood community before the scheme's terms were set in regulations "*to make sure the scheme will best serve those who it is intended for.*"[51]

In Scotland the First Minister told the Scottish Parliament that the Scottish Government "*will work collaboratively with the United Kingdom Government*" to put into effect the Prime Minister's promise about comprehensive compensation, and recognised "*how important it is that all those who are affected are able to access compensation as soon as possible.*"[52]

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[49] First Written Statement of James Quinault para 3 WITN7755001, Second Written Statement of James Quinault para 252 WITN7755003. Justine Gordon-Smith's account of the meeting she attended is instructive: "*John Glen MP had explained in our meeting his astonishment at how little had been achieved by his predecessors, that he had taken the advice of the Civil Service, appointed Sir Jonathan and excluded us, because he was acting with such haste that he felt he would miss deadlines for the Victims and Prisoners Bill to have involved us.*" Third Written Statement of Justine Gordon-Smith para 47 WITN2632085

[50] Hansard Statement by the Prime Minister 20 May 2024 pp1-2 RLIT0002476. The Welsh Government issued a statement the same day: "*The debate in the Senedd on 7 May confirmed our position in relation to the UK Government's proposal to set up an arm's length body to provide the vehicle by which compensation could be paid. Welsh Government officials will work with the UK Government to ensure Welsh beneficiaries and their families are recompensed in keeping with the Inquiry's interim report on compensation.*" Welsh Government written statement Infected Blood Inquiry: Initial Response to its Report 20 May 2024 p2 RLIT0002489

[51] Hansard Statement by the Paymaster General 21 May 2024 p2 RLIT0002477

[52] Statement to the Scottish Parliament by the First Minister on the Infected Blood Inquiry 21 May 2024 pp3-4 WITN2287088. A statement by the Minister of Health in the Northern Ireland Assembly recorded that "*Addressing the recommendations* [of the Inquiry] *will require a collective effort and coordination of communications in collaboration with the infected and affected community.*" The Official Report (Hansard) of the Northern Ireland Assembly 21 May 2024 p29 RLIT0002490

Up until 21 May 2024 no information regarding the proposed compensation scheme had been published. Not only had people infected and affected not been involved in the design and development of the scheme, they had been kept in the dark as to what the Government was planning. On 21 May, however, for the first time the Cabinet Office published online information about the compensation scheme,[53] and a short interim report from the Expert Group.[54]

The very next day the Prime Minister called a general election for 4 July 2024. The result was that Parliament was prorogued on 24 May, allowing just two sitting days for the "wash-up period" (the time between the announcement of an election and the subsequent dissolution of Parliament during which legislation in progress, which would not otherwise complete its passage through Parliament, can be passed before Parliament is dissolved). The Victims and Prisoners Bill was one of a small number of bills which were passed during the wash-up period. The Act, as it now became, received Royal Assent on 24 May 2024.

The June 2024 engagement exercise and the 2024 Regulations

There had been no engagement with, or involvement of, people infected and affected in the development of the scheme that was announced on 21 May 2024. In a paper dated 21 May from John Glen seeking the agreement of the Government's Domestic and Economic Affairs Committee to the proposed compensation scheme, the Paymaster General explained that:

> "*I propose to say that the proposed Scheme is subject to validation with representatives of the infected blood community, prior to being established in regulations. The validation*[55] *will test whether the tariff-based framework of compensation proposed takes proper account of the breadth of cases, and will sense check the Government's proposals on matters such as evidential requirements and support for applicants. Under the terms of the Victims and Prisoners Bill, the regulations to set up the Scheme must be laid within three months of the Bill receiving Royal Assent.*[56] *Accordingly, the scope and duration of the exercise will necessarily be limited.*"[57]

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[53] Infected Blood Compensation Scheme Proposal Summary 21 May 2024 RLIT0002493

[54] Infected Blood Inquiry Response Expert Group Interim Report 21 May 2024 RLIT0002478

[55] A proposal for "*Validation with the community*" had been put to the Deputy Prime Minister Oliver Dowden on 13 May 2024. It advised "*It is important that any engagement, regardless of whether this is part of a formal consultation or not, does not ask for views on matters which are already settled by the Government. This is part of the Government's Consultation Principles and there is a very high risk of successful legal challenge if the Government seeks views on matters where it has no intention of altering its decision. The Government must properly consider the views of those it chooses to consult with in its decision making before the final decision is made. This means that any validation engagement will need to be limited to matters where policy is still in development and views of the community are not already known.*" Submission on The Infected Blood Compensation Scheme Proposal Follow Up Advice 13 May 2024 pp20-21 CABO0000916

[56] Section 49 of the Victims and Prisoners Act 2024 imposed a legal duty on the Secretary of State or Minister for the Cabinet Office to establish a scheme for making payments to eligible people "*by regulations within three months of the passing of this Act*". Section 49(1) of the Victims and Prisoners Act 2024 p49 RLIT0002954

[57] Paper by the Minister for the Cabinet Office and Paymaster General: Infected Blood Inquiry Compensation Scheme 21 May 2024 para 7 CABO0000915

Thus, as described to the Inquiry:

> "*… 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.*"[58]
>
> "*Given that the intention under the recommendations of the Inquiry was to involve the scandal's victims, both infected and affected, in decisions surrounding the formulation of a compensation scheme, we were disheartened to learn that the scheme had already been devised well in advance of the announcement on May 21st, with little to no input from the infected blood community.*"[59]

The engagement exercise undertaken by Sir Robert Francis in June 2024 was indeed limited.[60]

It is instructive to look back at Sir Robert's oral evidence to the Inquiry in July 2022, when he said this about the role for those infected in the establishment of the scheme:

> "*… it is absolutely essential, and indeed you would probably expect me to say this as the Chair of Healthwatch and the President of the Patients Association, they should be involved in the creative process. This is not an area where I would be terribly happy with two panels going away in private and coming back six months later with a proposed solution and having a six-week consultation over the summer holidays to produce a result. You need some real involvement. As with everything else, but with this scheme in particular, it needs to carry the trust of the people who are most directly affected by it.*"[61]

What Sir Robert (rightly) said in July 2022 should not happen is what in fact happened. A single panel (not even two) – the Expert Group – deliberated, and advised the Government, in private over a number of months. There was then not even "*a six-week consultation over the summer holidays*", but a series of meetings which were, due to time constraints, compressed into a three week period.[62] There was no involvement of people infected and affected "*in the creative process*". There was no "*real involvement*". And as a result, the scheme devised by the Government did not, and for now does not, carry the trust of the people most directly affected by it.

On 4 July 2024 the general election took place and a new government was elected. Nick Thomas-Symonds became the Paymaster General and Minister for the Cabinet Office. There

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[58] Fifth Written Statement of Katherine Burt para 23 WITN6392288

[59] Fourth Written Statement of Andrew Evans para 2 WITN1213015

[60] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 pp6-8, p13 RLIT0002466. This is not a criticism of Sir Robert: the constraints of this exercise were not of his making.

[61] Sir Robert Francis Transcript 11 July 2022 pp144-145 INQY1000224

[62] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p13 RLIT0002466. An unpublished Engagement Explainer was produced by the Cabinet Office. Infected Blood Compensation Scheme - Engagement Explainer June 2024 WITN7752004

was, by virtue of the Victims and Prisoners Act, a statutory duty on the new Government to make the regulations to establish the compensation scheme by 24 August 2024. As Nick Thomas-Symonds told the Inquiry, "*I was confronted with a statutory deadline I had myself insisted upon in Opposition, and I was unequivocal that the system had to be driven throughout the summer to meet that deadline.*"[63]

On or about 12 July 2024 the report from Sir Robert Francis containing his recommendations following the engagement exercise was delivered to the Government. In it he recorded that a constant theme in all meetings was dissatisfaction with the process by which the proposals under consideration had been formulated and announced:

> "*I was told at every meeting that when published on 21 May* [sic]*, the Inquiry's report had been received with approval, and even rejoicing, and a feeling among the infected and affected community that their many complaints had been heard and accepted … However, the mood changed dramatically on the following day when the Government's proposals for compensation were released. These caused, I was told, great distress and anxiety and a feeling that what was announced fell far short of the expectations raised by the Inquiry's second interim report on compensation. During my meetings strong concerns were expressed, among them that:*
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> - *they did not believe that the engagement was a genuine attempt at obtaining feedback from the community but a 'tick-box exercise';*
> - *they had not received a full account of the proposals or the reasoning behind them;*
> - *they had had no input to the expert advisory committee;*
> - *the additional documentation given to them in preparation for the meeting did not enable them to understand many aspects of the proposals;*
> - *they had not had sufficient time to obtain advice and consult with those they represented.*
>
> *I quote from two written submissions received, one from a representative organisation:*
>
> > *'Those infected and affected by contaminated blood and blood products had less than 24 hours to digest the enormity of the Infected Blood Inquiry's final report before the Government published its compensation scheme.*
> >
> > *As the details of the scheme began to sink in, the feelings of elation and vindication which had resulted from the Inquiry's findings quickly evaporated, to be replaced by more familiar emotions of suspicion and uncertainty.*

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[63] Nick Thomas-Symonds Transcript 7 May 2025 p106 INQY1000283

> *It had happened again. The government had created a major scheme without one word of consultation with people it was designed to support. The blinkered way in which this scheme was built is shocking.*"'[64]

Sir Robert's report was subsequently published on 16 August 2024,[65] alongside further information from the Cabinet Office regarding the compensation scheme and the final report of the Expert Group.[66] Sir Robert made 74 recommendations, the majority of which were accepted by the Government, including the continuation of support payments.[67]

The Infected Blood Compensation Scheme Regulations 2024 were laid before Parliament on, and came into force on, 23 August 2024.[68] These Regulations enabled compensation to be paid to eligible infected people under the "core" route (details of the "supplementary" route and compensation for people affected would be mapped out in later regulations). A policy paper regarding the scheme was published by the Cabinet Office.[69]

Nick Thomas-Symonds told the Inquiry that when he took up his position on 7 July 2024 he was confronted with a situation where the money had not been allocated to the scheme by the previous Government, and that it was imperative that he secured funding from the Treasury. He also told the Inquiry that he did not think, given the work of the Expert Group, "*that seeking to repeat that exercise to expect different results was in the interests of victims whose compensation payments would then be subject to even further delay.*"[70]

In a debate on 23 October 2024 the Minister told Parliament that:

> "*these regulations are the next substantial step towards getting money to people who rightly deserve it. However, although there has been progress, the work is far from finished. A second set of regulations will provide for other elements of the compensation scheme, including compensation payments to those who are affected and for claims outside the core route. Subject to parliamentary approval, the Government aim for the second set of regulations to be in place by 31 March 2025, to support our intention … for those affected to start receiving*

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[64] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p9 RLIT0002466

[65] Sir Robert recognised that the work undertaken by the previous Government to design the scheme "*without the full benefit of the input of the community*" was "*not the best way to gain their trust in the proposals*" and that the engagement exercise was "*somewhat limited in time and scope*". Statement from Sir Robert Francis on his recommendations 16 August 2024 p2 RLIT0002468

[66] Government Update on the Infected Blood Compensation Scheme 16 August 2024 WITN7760006, Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 RLIT0002474

[67] The Minister informed Parliament on 2 September 2024 that the Government had accepted 69 of the 74 recommendations, adding that for the five that were not accepted "*it is because we believe that a different solution will be more practical and better for the victims.*" Hansard Statement by the Paymaster General 2 September 2024 p2 RLIT0002464

[68] Infected Blood Compensation Scheme Regulations 2024 (Statutory Instrument 2024 No. 872) RLIT0002479

[69] Infected Blood Compensation Scheme Summary 23 August 2024 RLIT0002945

[70] Nick Thomas-Symonds Transcript 7 May 2025 p107 INQY1000283

> *payments next year. There is shared determination across the House to deliver compensation as swiftly as possible and with the minimum delay.*"[71]

On 30 October 2024 the Government confirmed that it was prepared to meet the substantial costs of compensation when the Chancellor of the Exchequer, Rachel Reeves, announced in the Autumn Budget statement that £11.8 billion had been set aside to meet them.[72] It was later made clear that the administrative costs incurred by IBCA in administering this would be additional to this sum.[73] These were, and remain, important announcements. The sum recognised that, overall, compensation at a proper level to recognise the wrongs that had occurred should be, and would be, paid. Understandably it did not, however, deal with when individuals would receive their entitlements, nor how that sum would be fairly distributed between them.

The Expert Group

The Inquiry recommended (as had Sir Robert in his 2022 Compensation Study) that there should be two panels to advise the Chair and Board of the scheme at the outset: one of medical experts, one of lawyers.

> "*The clinical panel should encompass expertise at least in hepatitis and liver disease, HIV, transfusion, haemophilia, psychosocial aspects, and palliative care*" with consideration being given to whether it would be helpful to add "*advice on nursing care, occupational therapy, physiotherapy, haematology and other disciplines.*"[74]

The legal panel:

> "*should include those who regularly practise in the field of personal injury, who are familiar with assessing compensation in cases of severe injury. There should be at least one from each of the legal jurisdictions of the UK, England and Wales, Scotland, and Northern Ireland … 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.*"[75]

Critically, this Inquiry recommended that – since the panels would be there to "*advise on the scheme of banding and levels of award which are appropriate*" and "*their views will*

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[71] Hansard House of Commons debate on the Infected Blood Compensation Scheme 23 October 2024 p4 RLIT0002470

[72] Hansard House of Commons Financial Statement 10 October 2024 pp2-3 RLIT0002983

[73] IBCA X post 29 January 2025 RLIT0002984

[74] Infected Blood Inquiry Second Interim Report 5 April 2023 p23 INQY0000453, Infected Blood Compensation Study 14 March 2022 para 2.25 RLIT0001129

[75] Infected Blood Inquiry Second Interim Report 5 April 2023 p23 INQY0000453, Infected Blood Compensation Study 14 March 2022 para 2.25 RLIT0001129

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.*"[76]

The Government appointed the Expert Group on 22 January 2024, with further members added on 23 April 2024.[77] The Group was chaired by Professor Sir Jonathan Montgomery.[78] Its members (other than the Chair) comprised six clinicians,[79] an actuarial specialist[80] and a law firm.[81]

The Terms of Reference for the Expert Group required it to provide "*expert advice (legal and clinical)*" to the Government, "*working with officials to help develop a potential infected blood compensation framework*". This included but was not limited to:

- "*Reviewing existing work undertaken by officials on policy and cost analysis;*
- *Advising and supporting Government in defining eligible infections and severities;*
- *Providing advice and support to Government on potential compensation tariffs for the eligible infected and affected beneficiaries based on infection severities, within the principles agreed by Government;*
- *Advising and supporting Government to develop a potential compensation framework within the principles agreed by Government.*"[82]

It is plain from these Terms of Reference that the work undertaken by the Expert Group, and the advice which it provided to the Government, was expected to play a central role in the development of the compensation scheme.

The Expert Group regarded its Terms of Reference as precluding it from consulting with people who are infected or affected.[83] Given that its Terms of Reference, having provided that the Expert Group would consider a variety of evidence, added that "*For the avoidance*

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[76] Infected Blood Inquiry Second Interim Report 5 April 2023 p23 INQY0000453. See also Infected Blood Compensation Study 14 March 2022 para 2.40, para 2.76, para 9.11 RLIT0001129

[77] First Written Statement of James Quinault para 75 WITN7755001

[78] Professor Sir Jonathan Montgomery is a professor of healthcare law at University College London and chair of the Oxford University Hospitals NHS Foundation Trust.

[79] Professor Jane Anderson, Dr David Asboe, Dr Ahmed Elsharkawy, Professor Graham Foster, Professor Patrick Kennedy and Dr Ian Williams. The area of clinical expertise of Professor Anderson, Dr Williams (both of whom were also members of the Clinical Expert Group to the Infected Blood Inquiry) and Dr Asboe is HIV medicine. The other clinical members are hepatologists.

[80] Professor Alexander McNeil is a professor of actuarial science at the University of York.

[81] Browne Jacobson LLP. The Expert Group also received advice from "*health and care expert witness agencies*" including Apex Health Associates and Lisa Barnes & Associates Ltd. Infected Blood Inquiry Response Expert Group Final Report pp80-82 RLIT0002474

[82] Infected Blood Inquiry Response Expert Group Terms of Reference p4 RLIT0002487

[83] "*Our terms of reference did not permit us to take evidence directly from members of the infected community. We have done our best to take note of evidence received by the Inquiry and we have drawn on members' insights from their professional work. Had time and the restrictions of confidentiality permitted wider consultation, then we would have found that helpful.*" Also: "*Sir Brian recommended that the development of the scheme should involve the infected community. We support that principle, but our terms of reference precluded public engagement in our work.*" Infected Blood Inquiry Response Expert Group Final Report p5, p6 RLIT0002474

of doubt, 'evidence' … cannot be provided by the Expert Group inviting a person (or group of people) who is not ordinarily a member of the Expert Group to attend a meeting to provide such evidence", and given that the Terms of Reference imposed strict requirements of confidentiality on the members, the Expert Group was correct in regarding itself as unable to consult with those infected and affected. It rightly considered that this placed it at a disadvantage.[84]

The Expert Group did not contain the full range of expertise recommended by this Inquiry: in particular there was no psychosocial expertise; no clinician specialising in the treatment of people with bleeding disorders; and no clinician specialising in transfusion. It remains unclear why the Government did not seek a broader range of expert input: a Cabinet Office paper of 31 October 2023 describes the clinical expertise sought as "*clinical experience in infections/symptoms and stages they progress (HIV, HCV, HBV, HDV)*" but does not explain the exclusion of (in particular) psychosocial expertise.[85]

The appointment of the Chair (Professor Sir Jonathan Montgomery) was announced on 8 February 2024. The names of the other members of the Group were withheld. The Haemophilia Society responded:

> "*This announcement, which was made without any consultation with the infected blood community, raises more questions than it answers.*
>
> *We do not know which experts are on Professor Montgomery's team nor has their appointment process been publicised. We do not know the panel's remit or whether their advice will ever find its way into the public domain. … The work on the detail of the compensation scheme should be done by an independent arm's length body for compensation not by the Cabinet Office*".[86]

James Quinault, asked by Counsel to the Inquiry why the identities of the members of the Expert Group were kept secret, responded that it was "*to help the members of the committee*" because it would be unfair for them to have to account for their advice in public before they had even given it to the Government.[87] This reasoning is difficult to follow but

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[84] "*One of the principles that Sir Brian Langstaff recommended should underpin the scheme was community involvement. The engagement events convened by Sir Robert Francis provided us with important feedback that we have taken into account to revise some of our advice. We would have benefited from such feedback at an earlier stage. However, our terms of reference did not enable us to take direct evidence.*" Infected Blood Inquiry Response Expert Group Final Report p14 RLIT0002474. The Expert Group also noted that the "*speed with which we have needed to work in order to meet the Government's schedule and later statutory deadlines has made this task particularly challenging*" and that "*Our initial advice had to be provided to the Government without the opportunity to hear directly from those harmed by the contaminated blood scandal. There has been a limited opportunity for us to understand their thoughts on the advice that we have offered and the Government's decisions on the proposed Scheme.*" Infected Blood Inquiry Response Expert Group Final Report p16, p75, p77 RLIT0002474

[85] Submission on Infected Blood Inquiry Response: Expert Committee Recruitment Route 31 October 2023 para 4b CABO0000920

[86] Haemophilia Society Statement on government's appointment of Professor Sir Jonathan Montgomery as compensation advisor 8 February 2024 pp2-3 RLIT0002952

[87] James Quinault Transcript 8 May 2025 pp113-114 INQY1000284

it is unnecessary to consider it further. The documentation provided subsequently to the Inquiry reveals that the Cabinet Office's reasoning was in fact as follows:

> "*We will not be publishing names of members of the Expert Group as they will likely be approached or harassed by the community/interested stakeholders. COLA*[88] *have confirmed this approach. The Department has a duty of care towards these individuals and on this basis legal advice is that while it is beneficial to publish the names for transparency purposes, there is a clear policy reason in this instance for not doing so.*"[89]

This is an unjustifiable position for the Government to have taken.[90]

Moreover, there is no evidence that anonymity was sought by the members of the group. At the Expert Group's second meeting on 8 February 2024 the Cabinet Office agreed to review the position on publishing the names of the other members but at its third meeting the Cabinet Office confirmed that it "*maintained the position on its decision not to publish the Expert Group's names until the conclusion of the Expert Group's work.*"[91]

Although the Expert Group did not meet with the infected and affected, it did meet with representatives from NHSBT[92] and from the Advisory Committee on the Safety of Blood, Tissues and Organs (SaBTO), to discuss cut-off dates and approaches to determining probable infections.[93] It also met with medical assessors from EIBSS to discuss evidence and the burden of proof,[94] with the NHS Business Services Authority to further discuss the experience of EIBSS[95] and with representatives of the Horizon compensation scheme.[96] It met regularly with civil servants within the Cabinet Office. It is all the more extraordinary, therefore, that it was not permitted to engage with those whose interests should have been central to the Expert Group's work and the Cabinet Office's decision-making based on that work.

The minutes of the meeting of the Expert Group were not published,[97] and therefore people infected and affected were not able to follow or comment upon their deliberations. The first

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[88] Cabinet Office Legal Advisers.

[89] Submission on Infected Blood Expert Group: Chair and Clinician names 21 December 2023 para 19 CABO0000923. The document is erroneously dated 21 December 2024.

[90] The Cabinet Office might have reflected on the fact that the names of the 71 experts who formed the Inquiry's Expert Groups were public throughout the Inquiry, views having been sought on their nominations before they were confirmed. They were treated with proper respect by all who participated in the Inquiry. A fear of being approached is, on its own, a poor reason: if transparency were to yield to that, it seems of little value as a principle. As to harassment, no material has been made public that might provide an evidential foundation for this.

[91] Minutes of the Infected Blood Inquiry Response Expert Group 8 February 2024 p7 CABO0000925, Meeting of the Infected Blood Inquiry Response Expert Group 15 February 2024 p9 CABO0000925

[92] NHS Blood and Transplant, a core participant in the Inquiry.

[93] Minutes of the Infected Blood Inquiry Response Expert Group 22 February 2024 p11 CABO0000925

[94] Minutes of the Infected Blood Inquiry Response Expert Group 12 March 2024 p17 CABO0000925

[95] Minutes of the Infected Blood Inquiry Response Expert Group 15 March 2024 p20 CABO0000925

[96] Minutes of the Infected Blood Inquiry Response Expert Group 28 March 2024 p23 CABO0000925

[97] They have now been disclosed to, and published by, the Inquiry. Minutes of the Infected Blood Inquiry Response Expert Group CABO0000925

inkling that people had about the Group's thinking was when its very short interim report was published on 21 May 2024; its more detailed Final Report was only published on 16 August 2024, after the Government had taken final decisions regarding the scheme.

As (rightly) described by one Inquiry witness:

> "*The medical expert group advising on aspects of the framework at the beginning were anonymous. The Scheme's foundations have been formed essentially by a secret committee; we did not know who was on the expert group, what decisions they made in forming their conclusions and we do not know what their experiences were. The government deliberately decided to act without involving the community or the representatives. There has been no transparency in the process.*"[98]

Moreover, instead of a separate panel of lawyers, which might have included lawyers with experience of representing people infected and affected throughout the Inquiry, a single firm of solicitors was selected by the Cabinet Office to participate in the Expert Group, with no prior experience of infected blood and with no relationship with people infected and affected, and (having no offices in Northern Ireland nor in Scotland) with potentially only limited expertise in the approaches in Northern Ireland and Scots Law to compensation in personal injury and clinical negligence claims.

As described above, the decision to seek "*specialist clinical and legal expertise on personal injury/negligence*" was reached in October 2023. A submission dated 19 October 2023, drafted by the Cabinet Office's Infected Blood Response Team and addressed to the Minister for the Cabinet Office, advised that the policy and cost analysis on compensation had now reached the stage where progress required such expert advice.[99] The decision having been taken that the Government, rather than an Arm's Length Body, would "*hold accountability for the overall design of the scheme and tariff rates, in contrast to the recommendations of Sir Brian Langstaff*", it was considered that "*having an expert committee established may help to demonstrate, at least to some extent, that the compensation scheme has been designed by those with some independence from [the Government], which might enhance the credibility of the scheme with the infected blood community.*"[100] If it was hoped that the Expert Group would provide a veneer of independence, or make the Government's decisions regarding the scheme more acceptable, that hope was misplaced.

It is extraordinary that a Group whose role was evidently going to be so central to the compensation scheme was positively precluded from engagement with people infected and affected, in circumstances where the need for such engagement and direct involvement had been so strongly emphasised to the Government by both Sir Robert Francis and this Inquiry,

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[98] Written Statement of ANON para 2 WITN1150004

[99] Submission on Infected Blood Inquiry Response: Expert Advisers 19 October 2023 para 3 CABO0000918

[100] Submission on Infected Blood Inquiry Response: Expert Advisers 19 October 2023 para 7 CABO0000918

and (as it transpired) the experts themselves felt they would have been assisted by it. This was a process which was the opposite of transparent. It was the opposite of inclusive. And it was the very opposite of putting people infected and affected at the heart of the scheme.

October 2024 to March 2025

Between the making of the first set of Regulations in August 2024, and the making of the second set of Regulations on 31 March 2025, concerns about the scheme were voiced with increased frequency and intensity.[101]

During this period meetings between civil servants and people infected and affected took place,[102] as did meetings with the Minister.[103] However, with the exception of responding to the Haemophilia Society's concerns about the process for interim compensation payments to estates[104] and a consultation about two aspects of the unethical research award,[105] such engagement as took place was not for the purpose of trying to resolve the concerns and involving people in the remaining design of the scheme ahead of the second set of regulations. Rather it appears to have been "*to help understanding of the new laws*".[106]

On 12 February 2025 the Infected Blood Compensation Scheme Regulations 2025 were laid in draft. They had not been the subject of consultation. On the same date an addendum report of the Expert Group was published.[107] There had been no engagement with people infected and affected by the Expert Group for the purposes of that report in line with the restrictions to their Terms of Reference.

There was a short debate in the Delegated Legislation Committee on 24 March and the draft regulations were described as "*another step towards providing full and fair compensation to the people impacted by the infected blood scandal, who have already waited too long for justice.*"[108]

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[101] Including to the Inquiry. See by way of example the letter from the Haemophilia Society, the Hepatitis C Trust, Haemophilia Scotland, Haemophilia Northern Ireland, Tainted Blood and BTMK Solicitors 29 November 2024 HSOC0029916, the letter from Tainted Blood 5 December 2024 ANDE0000001 and the letter from Haemophilia Wales 4 December 2024 LKEL0000010

[102] See by way of example the meetings with James Quinault on 17-22 January 2025. Infected Blood Compensation Scheme: Meetings with Community Representative Groups 17-22 January 2025 WITN0622014

[103] See by way of example the meetings with the Minister on 11 December 2024 and 30 January 2025. First Written Statement of James Quinault paras 7 and 9 WITN7755001

[104] "*Significant changes in the interim compensation (estates) process have been made as a result of the Society's questioning and persistence in trying to resolve some difficult cases. For example, the Cabinet Office has issued at least two fact sheets to support scheme staff to provide guidance on issues the Society has raised.*" Written Statement of Katherine Burt para 33 WITN6392288

[105] This issue is considered later in this Additional Report.

[106] Draft Infected Blood Compensation Scheme Regulations 2025 Factsheet January 2025 p3 WITN6392300

[107] Infected Blood Inquiry Response Expert Group Addendum to Final Report 12 February 2025 WITN7762015

[108] Hansard Delegated Legislation Committee debate on the Draft Infected Blood Compensation Scheme Regulations 2025 24 March 2025 p3 RLIT0002485. The regulations were also debated in the House of Lords on 19 March 2025. Hansard House of Lords debate on the Infected Blood Compensation Scheme Regulations 2025 19 March 2025 RLIT0002972.

The Infected Blood Compensation Scheme Regulations 2025 came into force on 31 March 2025.[109]

Commentary

The further evidence that is now available shows that the conclusions in the Inquiry's 20 May 2024 Report regarding the Government's failure to act on compensation were, and remain, well-founded.

In light of the decision to reject the Inquiry's central recommendation of a scheme "*completely independent of Government*",[110] the Government should at the very least have ensured the active participation and involvement of infected and affected people in shaping the scheme. This Inquiry had recommended a scheme co-designed with infected and affected people. The scheme introduced by the Government is one in which the design and structure, the criteria for eligibility, and the tariffs, have been determined solely by the Government.

This Inquiry recommended a scheme in which the bands within which individual awards would fit would be determined following advice from clinical and legal panels which directly engaged with people infected and affected. Instead the Government established an Expert Group which operated in a fundamentally different way from the panels proposed by the Inquiry. The Expert Group did not contain a full range of appropriate expertise. Its Terms of Reference were not published until some time after it had started work. The names of its members (with the exception of its Chair) were withheld by the Cabinet Office on a basis which lacked any proper foundation. It was not permitted to engage with the very people for whose benefit the scheme was supposed to be designed. Indeed, Sir Jonathan Montgomery as Chair repeatedly drew attention in the Expert Group's published reports to the fact that the group would have benefited from direct contact with people who were infected and affected, and yet was denied this.

Bill Wright,[111] Co-Chair of Haemophilia Scotland, told the Inquiry on 7 May 2025 that the architecture of what has been set up was "*fundamentally flawed*" for two reasons:

> "*First of all, the approach taken, in terms of the foundation of the Montgomery report and how that was arrived at. And, secondly, the calling of the election by*

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[109] Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) RLIT0002944, Infected Blood Compensation Scheme Summary 31 March 2025 RLIT0002481

[110] "*It must be completely independent of Government, and must be seen to be, even though (a) the Government must fund it and (b) the accounting officer of the scheme should report annually to Parliament upon the way in which it has discharged its duties.*" Infected Blood Inquiry Second Interim Report 5 April 2023 p18 INQY0000453

[111] Bill Wright OBE was a founding Trustee and then Chair, now Co-Chair, of Haemophilia Scotland and in that capacity a member of the Scottish Financial Review Group (2015) and the Clinical Review of the Impacts of Hepatitis C (2018). The First Minister paid tribute to his leadership in the Scottish Government's response to the Inquiry Report. Statement to the Scottish Parliament by the First Minister on the Infected Blood Inquiry 21 May 2024 p3 WITN2287088

> *the Prime Minister 48 hours after he made an apology in Parliament, the same day as the Inquiry report was published*".[112]

The result was "*a situation where trust and confidence, both in Government and, unfortunately, to a certain extent in IBCA, has collapsed*". He contrasted the way in which the Government approached the Expert Group with what had happened in Scotland after the Penrose Inquiry, where there were discussions with the Scottish Government "*in a collegiate manner. They set up a financial review which involved us, civil servants and other stakeholders, along with our lawyers, and we reached a proposal to set up the Scottish Infected Blood Support Scheme*". This was followed by a "*further collegiate approach when we had the clinical review*":

> "*the clinical review again involved us, and it involved some of the top doctors in Scotland … They came up with proposals which built in trust. Those doctors realised that we could be trusted. And we worked positively with them. We exchanged telephone calls with them, and we reached a proposal for a self-assessment scheme where individuals in Scotland could say where they were up to in terms of their hepatitis C journey and have support accordingly.*"[113]

By contrast, "*None of that has happened under what has been proposed by the UK Government.*" Indeed, as Bill Wright emphasised, "*Government did not trust us*" to sit on, or talk to, the Expert Group. As he observed, "*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.*"[114]

The role of the Expert Group without any consultation with the infected and affected community is said to be "*where the primary errors and angst are flowing from.*"[115] The absence of involvement from people infected and affected, and their legal representatives, at the critical stages early in the development of the scheme is "*probably the single biggest fundamental flaw in the whole process and undermines everything that has happened since the Public Inquiry reported.*"[116]

Such involvement of people infected and affected as has taken place has been limited. The Inquiry has received numerous accounts regarding the quality of the engagement

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[112] The merits of the decision to call a general election are not for the Inquiry to consider. However, the effect, as Bill Wright described, was that the legislation and regulations were rushed through, at a time when the opportunity for public consultation was restricted due to the election: "*In effect, there was a vacuum.*" William Wright Transcript 7 May 2025 p11 INQY1000283

[113] William Wright Transcript 7 May 2025 pp11-12 INQY1000283. He also noted that the Scotland Infected Blood Support Scheme achieved a 97% satisfaction rate. Scottish Infected Blood Support Scheme 2023 Customer Satisfaction Survey p4 RLIT0002351

[114] William Wright Transcript 7 May 2025 p13 INQY1000283. See similarly the oral evidence of Nigel Hamilton Transcript 7 May 2025 p33 INQY1000283

[115] Fourth Written Statement of Bruce Norval para 7 WITN2235014

[116] Second Written Statement of Nigel Hamilton para 48 WITN2340014; see also the Fifth Written Statement of Katherine Burt para 28 WITN6392288

with the Cabinet Office and IBCA. People describe being talked at, rather than talked to.[117] They describe the Government as "*only doing lip service to this engagement … a tick-box exercise.*"[118] What is described by them is a "*complete disregard for the patient voice*", with "*no real attempt to engage.*"[119] Meetings with the Cabinet Office have been described as providing no "*substantive or meaningful engagement, but merely lip-service and to rubber stamp an engagement process taking place. The appearance of being listened to was there but it transpired that the decision-making process had already been completed by Cabinet Office.*"[120] There has been particular criticism of a meeting held by the Cabinet Office on 23 May 2024, and a meeting with the Minister on 11 December 2024.[121]

As described by one individual, "*it feels like we are an afterthought and are now spectators in the process.*"[122] Another, describing a meeting in January 2025, states that "*This is not meaningful engagement … It is just lip service and tinkering around the edges.*"[123]

I note that Nick Thomas-Symonds agreed that the previous Government did not need to await the Inquiry Report in order to work out a compensation scheme; that work should have begun at an earlier point than it did; and that the public was misled as to the speed with which the previous Government was setting up the scheme.[124] He was right to say so.

Given the combination of factors identified above – the slow progress by the previous Government, their failure to involve people infected and affected in the design of the scheme, their establishment of the Expert Group, the general election, and the statutory deadline which required the scheme to be established in regulations by 24 August 2024 – I recognise the difficulty and dilemma facing the Minister in July and August 2024, as well as

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[117] See for example the oral evidence of Alan Burgess Transcript 7 May 2025 p16 INQY1000283 and of Nigel Hamilton Transcript 7 May 2025 pp35-36 INQY1000283

[118] Mary Grindley Transcript 7 May 2025 p42 INQY1000283. Samantha May of the Hepatitis C Trust described "*token engagement*", with "*no consultation and input*" into "*the secret expert group*": "*Why weren't -- why wasn't the expertise of ourselves and the Haemophilia Society, who have been working with this group, infected and affected, for decades, why weren't we part of that process? And why weren't the community part of that process?*" Samantha May Transcript 7 May 2025 pp51-52 INQY1000283

[119] Katherine Burt Transcript 7 May 2025 p63 INQY1000283

[120] Second Written Statement of The Scottish Infected Blood Forum para 14 WITN7165016; see also para 20.

[121] Second Written Statement of Stuart McLean para 4a (meeting of 23 May) and paras 4d and 7 (meeting of 11 December 2024) WITN0653028, Written Statement of ANON para 6 (meeting of 11 December 2024) WITN1150004, Second Written Statement of Nigel Hamilton paras 22-23 (meeting of 23 May) and para 25 (December meeting) WITN2340014, Second Written Statement of Lynne Kelly para 9 (May 23 meeting) and para 13 (December meeting) WITN3988094, Fifth Written Statement of Katherine Burt para 27 (December meeting) WITN6392288, Second Written Statement of Richard Newton para 26 (December meeting) WITN6897002, Written Statement of ANON and Alan Burgess paras 4-6 (23 May meeting) WITN7752001, Written Statement of John Dearden on behalf of Haemophilia Scotland para 10 (23 May meeting) WITN7754001

[122] Fourth Written Statement of Sean Cavens para 11 WITN1146047

[123] Third Written Statement of ANON para 25 WITN1791047. See also the evidence of Nigel Hamilton "*I am bound to say that I do not think we have really had 'engagement', rather, we have meetings where we are updated*" and the evidence of John Dearden "*These events from our experience are about government telling us what they are doing, allowing minimum time for questions, with generally no answers or rational explanation of the government's plans. This does not equate in our minds to engagement.*" Second Written Statement of Nigel Hamilton para 47 WITN2340014, Written Statement of John Dearden on behalf of Haemophilia Scotland para 47 WITN7754001

[124] Nick Thomas-Symonds Transcript 7 May 2025 p114 INQY1000283

his desire to avoid "*yet more drift, yet more problems of delay.*"[125] He had been keen when in opposition to push forward progress on compensation; and although he acknowledged that he could have set the scheme up in a different way, he judged that to try to go back and disturb that would create an even greater delay than the one already faced "*and that has been the dilemma throughout.*"[126]

It has to be acknowledged that by the time the first regulations came into force in August 2024 a course had already been set, and approved by Parliament, that made it highly unlikely there would be any significant change to the shape of the scheme, such that there was only limited scope for meaningful consultation about the design of that scheme. It also made it highly likely that engagement would seem to be more like an explanation of decisions already taken about the scheme than involvement of interested parties in determining its essential characteristics.

The Minister made some alterations – he arranged for the inclusion of adult siblings and some changes to the award in respect of unethical research and its scope[127] – but was and remains concerned lest any change added further to delay.[128]

Since August 2024 there has, however, been a missed opportunity to examine with people infected and affected their deep and profound unhappiness with important aspects of the scheme, **before** the making of the 2025 Regulations. John Dearden, Chair of Haemophilia Scotland, acknowledging the encouraging step of the Minister accepting most of Sir Robert Francis' recommendations in summer 2024, suggests that this progress "*stands in stark contrast to the disappointing lack of engagement with the government in the months that followed.*"[129]

Anyone who has read the Inquiry Report of May 2024 will recognise that there has been a repetition of the mistakes of the past in the way in which government (both before and after the general election) has responded. Dr Justine Gordon-Smith, campaigner, observes in her statement to the Inquiry that "*nothing has changed post inquiry. The government is in no way transformed. We should be involved in determining how we are consulted with and the form of engagement and timeframes we are provided with. When we are asked to discuss amendments or changes to be made to the Scheme, we should be invited to have a proper meaningful discussion.*"[130] Lynne Kelly, Chair of Haemophilia Wales, explains how "*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*

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[125] Nick Thomas-Symonds Transcript 7 May 2025 p117 INQY100283

[126] Nick Thomas-Symonds Transcript 7 May 2025 p122 INQY100283

[127] And he pointed out in evidence that he had earlier arranged for the continuation of support payments

[128] See generally his evidence at Nick Thomas-Symonds Transcript 7 May 2025 pp121-126 INQY100283

[129] Written Statement of John Dearden on behalf of Haemophilia Scotland paras 73-74 WITN7754001

[130] Third Written Statement of Justine Gordon-Smith para 43 WITN2632085

refusal to move or take on board suggestions for change".[131] John Dearden notes that "*We have returned to a paternal 'we know what is best for you' approach*".[132]

Baroness Featherstone, speaking on 19 March 2025 in the debate in the House of Lords regarding the 2025 Regulations, reported that:

> "*There has been woefully insufficient engagement with victims and campaigners, who feel that the Government have not adequately involved them in the development and implementation of the scheme, which has led to a feeling of marginalisation and distrust towards the authorities overseeing the process. It sends them right back to the years when they came as supplicants to successive Governments …*"[133]

The harm which all this has caused is evident in everything that has been said by people infected and affected – in statements, emails, letters and calls to the Inquiry – over recent months. It displays much of what the Inquiry's psychosocial experts described as "*initial frustration and anger*" progressing to "*longer term distress, dejection and hopelessness.*"[134]

Andrew Evans told the Inquiry on 7 May 2025 what had been said to him by another:

> "*This past year has not simply caused more psychological damage; it has brought a new and different layer of psychological pain, another layer I've had to endure, adapt to and fight every day to not let it take over my life. I have spent more than 30 years fighting trauma, exclusion and the constant struggle to keep my life together. I have fought every day to keep the darkest thoughts from consuming me. What has happened since the compensation scheme was announced has pushed that fight to its absolute limit and now I am utterly exhausted … The anguish is beyond words.*"[135]

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[131] Second Written Statement of Lynne Kelly para 81 WITN3988094; see also the Fifth Written Statement of Katherine Burt para 57 WITN6392288

[132] Written Statement of John Dearden on behalf of Haemophilia Scotland para 56 WITN7754001

[133] Hansard House of Lords debate on the Infected Blood Compensation Scheme Regulations 2025 19 March 2025 RLIT0002972. After the debate Baroness Featherstone, Baroness Campbell, Baroness Brinton and Baroness Finlay wrote to the Inquiry expressing the view that "*despite the Government's good intentions, the reality and experience of those infected and affected by contaminated NHS blood products remains wanting … the way that many victims are being treated now by the IBCA and the Government is reminiscent of the way they were treated throughout the 40 years of pleading for justice.*" Letter from four members of the House of Lords 28 March 2025 LFEA0000001

[134] Expert Report to the Infected Blood Inquiry: Psychosocial Issues January 2020 EXPG0000003, Expert Report to the Infected Blood Inquiry: Psychosocial Issues (Supplementary) September 2020 pp18-19 EXPG0000042

[135] Andrew Evans Transcript 7 May 2025 pp19-20 INQY1000283. See also his Fourth Written Statement: "*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 deal 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*

He explained that:

> "*People brought to tears by relief of the publication of the Inquiry's Final Report have told me that the very next day when the Government responded, their world and hopes crumbled again. They say that since that day they felt nothing but despair; that they have lost all hope of ever getting justice.*"[136]

And he observed that:

> "*many, if not all, of these issues might have been avoided had the community been given access to feed into the expert report. This didn't happen, and the scheme was effectively written in stone before we even laid eyes on it. Compounding this is the sheer frustration that we were told that compensation would have to wait until the Inquiry's Final Report, yet given the timing of the announcement of the scheme a day after that report, its clear there was no reason to have waited, and the Final Report bore no significance, no relevance to the scheme. Indeed, there was clearly no time to have read it, let alone to have devised a scheme as a result of it. It was done well in advance and should have included us during its formulation. The way that this has been handled since the second Interim Report to date is, to my mind, the same line to take tactics, defensiveness and lack of candour that we've been fighting for the past four decades.*"[137]

These words are fully justified.

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has resulted in further exacerbation of physical illness as well as the obvious mental impact." Fourth Written Statement of Andrew Evans para 15 WITN1213015

[136] Andrew Evans Transcript 7 May 2025 p22 INQY1000283

[137] Andrew Evans Transcript 7 May 2025 pp25-26 INQY1000283

3 Operation of the Compensation Scheme

It is vitally important that the scheme to compensate people who suffered as a result of the use of infected blood and blood products carries the trust of those it is set up to benefit. An absence of trust exacerbates and perpetuates the harms which they have already experienced. However, it is beyond doubt that the events since 2020 set out in the foregoing pages of this Additional Report, describing how and why matters have reached their current stage, have caused the trust of many to have been lost, at least for now, or put seriously in jeopardy. Action needs to be taken without delay if it is ever to be regained.

It will be obvious from any comparison of the framework for the compensation scheme recommended by the Inquiry in its Second Interim Report with the scheme as enacted, that it is not designed to operate as the Inquiry recommended. However, I have become convinced that a number of changes, both to the scheme itself (involving significant improvements in the detail of the scheme),[138] and to the way in which the scheme is currently operating, will improve the speed with which compensation can be delivered, allow it to operate more fairly, and be more open and transparent.

To set the scene for the chapter on *Recommendations*, this chapter sets out what the law provides, before turning to the relationship between IBCA and the Cabinet Office and then what in practice has been the approach of IBCA to involving people infected and affected, transparency, the role of the clinical assessors, the role of legal representatives, the reasons for IBCA's slow start and lastly IBCA's internal reviews.

The statutory framework for the Infected Blood Compensation Authority ("IBCA")

IBCA was established by Parliament under section 48(1) of the Victim and Prisoners Act 2024 ("the Act"), which provides that "*A body corporate called the Infected Blood Compensation Authority is established.*"[139]

Structure and appointments

The Act provides that IBCA itself is to consist of (a) a Chair (who is to be a non-executive member), (b) at least three, but not more than six, other non-executive members, (c) a Chief Executive, and (d) at least two, but not more than five, other executive members.[140]

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[138] These are set out in the later chapters of this Additional Report: *HIV transmitted before 1982, Hepatitis, Specific Concerns, People affected* and *Bereavement after 31 March 2025*.

[139] Paragraph 48 of the Victims and Prisoners Act 2024 p49 RLIT0002954

[140] Paragraph 1 of Schedule 1 to the Victims and Prisoners Act 2024 p85 RLIT0002954. Executive members are those who play an active part in the management and operations of the organisation and in implementing policy and procedures agreed by the board, and thus deliver those policies; non-executive directors have no hands-on role in delivering policies, but have an oversight of what is being done and participate in the development of the policies and procedures which are to be executed.

Under the Act the Chair of IBCA is to be appointed by the Minister for the Cabinet Office.[141] The first three non-executive members are to be appointed by the Minister for the Cabinet Office. The other non-executive members are to be appointed by the Chair.[142] A person may not be appointed as a non-executive member if the person is a member of IBCA's staff.[143] The Chief Executive and other executive members are to be appointed by the Chair, and are to be members of IBCA's staff.[144]

Relevant Powers of IBCA

IBCA has the power to appoint employees and "*make such other arrangements for the staffing of IBCA as it determines*".[145] It may also appoint such committees and sub-committees as it considers appropriate, and those committees and sub-committees can consist of or include people who are neither members of IBCA, nor members of staff of IBCA.[146]

IBCA is empowered to determine its own procedure and the procedure of any of its committees or sub-committees.[147] It may "*do anything it thinks appropriate for the purposes of, or in connection with, its functions.*"[148]

As to those functions, IBCA is able to delegate any of them to: a member of IBCA; a member of IBCA's staff authorised for that purpose; or any committee or sub-committee.[149] It is required to provide to the Minister such information relating to its functions as he or she may request.[150]

Funding

IBCA's funding comes from the Cabinet Office: the Minister for the Cabinet Office must pay to IBCA (a) such sums as are required to meet payments made by IBCA under the

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[141] Paragraph 2(1) of Schedule 1 to the Victims and Prisoners Act 2024 p85 RLIT0002954. The Act, when describing the powers and functions of the Government, makes them exercisable by "*the Secretary of State or the Minister for the Cabinet Office.*" As, in practice, the relevant powers have been exercised by the Minister for the Cabinet this Report will refer only to the Minister rather than the Secretary of State.

[142] Paragraph 2(2) of Schedule 1 to the Victims and Prisoners Act 2024 p85 RLIT0002954

[143] Paragraph 2(3) of Schedule 1 to the Victims and Prisoners Act 2024 p85 RLIT0002954

[144] Paragraph 3 of Schedule 1 to the Victims and Prisoners Act 2024 p86 RLIT0002954. An interim Chief Executive may be appointed by the Minister for the Cabinet Office until the appointment of the first Chief Executive by the Chair. The powers of an interim Chief Executive are circumscribed in the sense that they may incur expenditure and do other things in the name of and on behalf of IBCA, but in exercising those powers must act in accordance with any directions given by the Minister for the Cabinet Office: Paragraph 8(2) and (3) of Schedule 1 to the Victims and Prisoners Act 2024. The Inquiry has been informed by the Cabinet Office that no such directions have been issued.

[145] Paragraph 7 of Schedule 1 to the Victims and Prisoners Act 2024 p87 RLIT0002954

[146] Paragraph 9 of Schedule 1 to the Victims and Prisoners Act 2024 p88 RLIT0002954

[147] Paragraph 10 of Schedule 1 to the Victims and Prisoners Act 2024 p89 RLIT0002954

[148] Paragraph 19 of Schedule 1 to the Victims and Prisoners Act 2024 p92 RLIT0002954. However, in doing so it must have regard to the need to exercise its functions "*effectively, efficiently and economically*". Paragraph 11(1) of Schedule 1 to the Victims and Prisoners Act 2024 p89 RLIT0002954. This is a requirement commonly found in legislation governing the functions of public bodies.

[149] Paragraph 11(2) of Schedule 1 to the Victims and Prisoners Act 2024 p89 RLIT0002954

[150] Paragraph 16 of Schedule 1 to the Victims and Prisoners Act 2024 p91 RLIT0002954

infected blood compensation scheme, and (b) such other sums as the Minister considers are reasonably sufficient to enable IBCA to carry out its functions.[151]

What IBCA is not intended to be

The Act provides that "*IBCA is not to be regarded (a) as the servant or agent of the Crown, or (b) as enjoying any status, immunity or privilege of the Crown*" and that service as a member, or a member of staff, of IBCA "*is not service in the civil service of the State.*"[152] In this respect, IBCA differs as a matter of law from the Skipton Fund which was set up specifically as an agent of the Department of Health and had no independence from the Department of Health.[153]

Regulations: the legal framework

As explained by Nick Thomas-Symonds during his oral evidence, the Act imposed a legal duty on the Minister for the Cabinet Office to establish a scheme for making payments to eligible people "*by regulations within three months of the passing of this Act*".[154] The regulations "*must provide for payments under the scheme to be made by, and the scheme to be otherwise administered by*" IBCA.[155]

The Act provides that the amount of a payment under the scheme is to be determined in accordance with the regulations.[156] The regulations may make provision for the amount payable to eligible people to be a specified amount, or an amount within a specified range, or not to exceed a specified amount.[157] They may also make provision for interest to be payable on payments, or for the amount of any periodic payment to be increased to take account of changes in the value of money.[158]

The regulations made by the Minister may deal with the procedure for the making and deciding of applications for payments under the scheme (including making provision about evidence).[159]

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[151] Paragraph 12 of Schedule 1 to the Victims and Prisoners Act 2024 p89 RLIT0002954. Paragraph 13 requires IBCA to prepare a report on the exercise of its functions during the financial year and send that to the Cabinet Office, for the Minister to lay before Parliament.

[152] Paragraph 17(1) and 17(3) of Schedule 1 to the Victims and Prisoners Act 2024 p91 RLIT0002954

[153] Infected Blood Inquiry Report 20 May 2024 Volume 6 p202 INQY0001006

[154] Section 49(1) of the Victims and Prisoners Act 2024 p49 RLIT0002954, Nick Thomas-Symonds Transcript 7 May 2025 pp116-118 INQY1000283

[155] Section 49(5) of the Victims and Prisoners Act 2024 p50 RLIT0002954

[156] Section 50(1) of the Victims and Prisoners Act 2024 p50 RLIT0002954

[157] Section 50(2) of the Victims and Prisoners Act 2024 p50 RLIT0002954. "*Specified*" means specified in the regulations: Section 50(6) of the Victims and Prisoners Act 2024 p50 RLIT0002954

[158] Section 50(3) of the Victims and Prisoners Act 2024 p50 RLIT0002954

[159] Section 51 of the Victims and Prisoners Act 2024 p50 RLIT0002954

The regulations may make provision for IBCA itself to review decisions taken under the scheme, and must confer a right of appeal to the First-tier Tribunal against a decision taken under the scheme.[160]

IBCA has a wide power under the Act to require the provision of information to it for the purposes of any matter connected with the administration of the scheme.[161]

Under the Act the Minister for the Cabinet Office has the power to make "*such arrangements as they consider appropriate for the provision of support and assistance to applicants (or potential applicants) for compensation under the infected blood compensation scheme.*"[162]

IBCA's organisational structure in practice

IBCA has an interim Chair, Sir Robert Francis KC,[163] an interim Chief Executive, David Foley, and a senior leadership team.[164] Each member of the senior leadership team has formerly had a senior role within the civil service.[165]

There are six non-executive directors appointed to IBCA. Their backgrounds are varied (but do not include careers in the civil service) and are detailed on IBCA's website. They include Sir Rob Behrens, the former Parliamentary and Health Service Ombudsman, and initially included Paula Sussex who now holds that position.[166]

David Foley has told the Inquiry that strategic decision-making within IBCA comes from the Board and from an Executive Committee (the latter comprising the Chief Executive and the members of the senior leadership team).[167]

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[160] Section 52 of the Victims and Prisoners Act 2024 p51 RLIT0002954

[161] Section 53 of the Victims and Prisoners Act 2024 p51 RLIT0002954

[162] Section 55 of the Victims and Prisoners Act 2024 p53 RLIT0002954. These arrangements may be for the provision of support and assistance by IBCA or "*by any other person*".

[163] Sir Robert's initial appointment has been extended for a further 18 months. Hansard Statement to Parliament by the Paymaster General 14 May 2025 p2 RLIT0002957

[164] IBCA Senior Organogram WITN7757005. The members of the leadership team are each described (currently at least) on IBCA's website as "*Interim*". IBCA website Our leadership RLIT0002958

[165] David Foley was previously the Director of Public Bodies, Governance and Priority Projects in the Cabinet Office. The Interim Director of Finance (as described on IBCA's website, but described on the IBCA Senior Organogram WITN7757005 as Director, Legal, Finance & Commercial) was previously the Chief Financial Officer at the Cabinet Office and Director with responsibility for both the Cabinet Office's Finances and Corporate Strategy. The Interim Director of HR is described on IBCA's website as "*an experienced Civil Servant and HR professional*" who has worked in the Department of Business and Trade, HMRC and the Home Office and as Director of People at the Care Quality Commission. The Interim Director of Communications was previously Deputy Director for Service Transformation Communications at HMRC. The Interim Director for Data was previously Chief Data Officer at HM Treasury. The Interim Director of Digital and Service Owner for IBCA previously led on the design and development of services at the Department for Work and Pensions. The Interim Director of Operations was previously Deputy Director for National Insurance, Child Benefit and Childcare Services in HMRC.

[166] IBCA website Our leadership RLIT0002958, IBCA Press Release *New appointments to board of Infected Blood Compensation Authority* 10 October 2024 WITN7757004

[167] First Written Statement of David Foley para 21 WITN7757001

The Executive Committee has established a sub-committee, known as the Policy Forum, whose terms of reference are:

> *"a. review operational policy options and positions relating to the Compensation Service, and either ratify them or recommend them for consideration by ExCo.*[168]
>
> *b. to prepare a recommendation to take to ExCo on strategic and/or potentially contentious operational policy decisions.*
>
> *c. ensure critical but highly technical operational policy decisions and positions are properly considered and ratified in a timely manner.*
>
> *d. explore and identify policy gaps and requirements, reverting to a-c above if necessary."*[169]

The core members of the Policy Forum come from within IBCA, but the Terms of Reference note that "*Subject-matter experts such as IBIRT and UCs may be invited but in an advisory only capacity.*"[170] "IBIRT" refers to the Infected Blood Inquiry Response Team within the Cabinet Office and "UCs" to user consultants.[171]

In his written statement to the Inquiry on 24 February 2025, David Foley explained that IBCA's staff will be public servants[172] but that this requires IBCA to be established as an employer with the requisite HR policies and systems (including the ability to provide staff with pensions). He stated that to ensure that putting in place these arrangements did not delay the making of compensation payments, IBCA "*has therefore begun operations staffed by civil servants with the clear intent and understanding that staff will be employed directly by IBCA as soon as possible.*"[173] The position as at 8 May 2025, when David Foley gave oral evidence to the Inquiry, was that "*all of our employment is still under the aegis of the Cabinet Office. So everybody who is employed to work on IBCA is employed by the Cabinet Office as a civil servant.*"[174] He added that "*once we're in a position to employ people ourselves, then all of those people who are in those roles will transfer into the employment of the authority, and from that point on, everybody we recruit will be employees of the authority, not the Cabinet Office.*" His expectation was that this will have happened by October 2025.[175]

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[168] ExCo refers to the Executive Committee

[169] IBCA Policy Forum Terms of Reference para 2.1 WITN7757013

[170] IBCA Policy Forum Terms of Reference para 4.1 WITN7757013

[171] A Cabinet Office official attended the Policy Forum's meeting on 21 March 2025. Third Written Statement of James Quinault para 8 WITN7755006, IBCA Policy Forum Minutes 21 March 2025 WITN7757014

[172] As distinct from civil servants.

[173] First Written Statement of David Foley para 24 WITN7757001

[174] This does not include people who are engaged as contractors, rather than employees.

[175] David Foley Transcript 8 May 2025 pp12-13 INQY1000284

The relationship between IBCA and the Cabinet Office: IBCA as an Arm's Length Body

A framework document dated March 2025 sets the "*broad governance framework within which IBCA and the Cabinet Office operate.*"[176] This describes IBCA as a "*non-departmental public body (NDPB)*".[177] It summarises IBCA's statutory duties and functions (as derived from the Victims and Prisoners Act and from the Regulations) as being to:

- "*administer the Infected Blood Compensation Scheme and determine and make payments to eligible people as set out by the Infected Blood Compensation Scheme Regulations 2024 and any amendments to those regulations or additional regulations made under the Act;*[178]
- *decide whether a person applying to the Scheme is eligible for compensation under the regulations and inform the applicant of that decision;*
- *review decisions taken under the Infected Blood Compensation Scheme and inform the applicant of the right to review and appeal decisions under the Scheme and the time period these rights must be exercised within;*
- *keep proper records and provide the information and reports required by the Minister for the Cabinet Office;*
- *retain any payments it recovers and use for the purposes of administering the Scheme or making compensation payments under the Scheme; and*
- *have regard to the need to exercise its functions effectively, efficiently and economically;*
- *require relevant persons (listed in the Victims and Prisoners Act) to cooperate with IBCA on any matter connected with the making of payments under the Scheme;*
- *appoint employees, committees and subcommittees;*
- *determine its own procedure and the procedure of any committees or sub-committees;*
- *delegate any of its functions to any member of the IBCA, member of the IBCA's staff authorised for that purpose, or any committee or subcommittee.*"[179]

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[176] IBCA Framework Document March 2025 para 1.2 WITN7755002

[177] IBCA Framework Document March 2025 para 3.2 WITN7755002

[178] The Infected Blood Compensation Scheme Regulations 2025 came into force on 31 March 2025.

[179] IBCA Framework Document March 2025 para 5.2 WITN7755002

IBCA's strategic aims are defined as follows:

- "*to recognise and compensate every eligible person impacted by infected blood with great care and respect and within as short a time as is consistent with fair, compassionate and accurate processing of claims; and*
- *To make it easy for people who are eligible to get the compensation and support they are entitled to.*"[180]

The framework document states that IBCA has been set up "*to have operational freedom to make the necessary decisions to deliver compensation*" in line with the Regulations, including decisions on individual compensation claims.[181]

There are circumstances in which IBCA is expected to consult the Cabinet Office: including where decisions on the administration of the scheme might involve novel, contentious or precedent-setting expenditure and require Accounting Officer approval, or where decisions are likely to result in significant changes to the expected profile of compensation spend agreed between IBCA, the Cabinet Office and HM Treasury.[182]

The framework document explains that the Minister for the Cabinet Office is responsible for "*the policy framework within which IBCA operates (as set out in regulation)*" and for "*approving the performance framework within which IBCA will operate*". The Minister should also be consulted on IBCA's Business Plan and Strategy.[183]

The framework document describes the role and responsibilities of the Principal Accounting Officer. The Principal Accounting Officer, who is the Permanent Secretary of the Cabinet Office, is responsible for advising the Minister on matters which include an appropriate framework of targets and objectives for IBCA, a delegated budget for IBCA, and how well IBCA is achieving its strategic objectives and whether it is delivering value for money.[184] The Principal Accounting Officer is also responsible for ensuring arrangements are in place in order to monitor IBCA's activities and performance and address significant problems in IBCA.[185]

Under the framework document the Infected Blood Inquiry Response Team ("IBIRT") within the Cabinet Office will liaise with IBCA on a monthly basis to review performance against plans, achievement against targets and expenditure against allocations. IBIRT "*will also take the opportunity to explain wider policy developments that might have an impact on IBCA.*"[186]

The framework document describes the responsibilities of IBCA's Chief Executive, Chair and Board. Insofar as the Board is concerned, its list of responsibilities include "*ensuring*

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[180] IBCA Framework Document March 2025 para 6.2 WITN7755002

[181] IBCA Framework Document March 2025 para 7.1 WITN7755002

[182] IBCA Framework Document March 2025 para 7.1 WITN7755002

[183] IBCA Framework Document March 2025 para 8.6 WITN7755002

[184] IBCA Framework Document March 2025 para 9.5 WITN7755002

[185] IBCA Framework Document March 2025 para 9.6 WITN7755002

[186] IBCA Framework Document March 2025 para 10.2 WITN7755002

that in reaching decisions, the Board takes into account guidance issued by the Cabinet Office."[187] The Chair's responsibilities also include "*ensuring that the Board, in reaching decisions, takes proper account of guidance provided by the responsible Minister or the Cabinet Office.*"[188]

There is a recent illustration of how these responsibilities and relationships work in practice. The minutes of the meeting of the Board of IBCA record that on 1 April 2025 Nick Thomas-Symonds, as Minister for the Cabinet Office, together with the Cabinet Office Permanent Secretary, met Sir Robert Francis and David Foley. They reported to the Board on 7 April that at that meeting the Minister had expressed:

> "*concerns at the pace of IBCA's delivery and wanted proposals and ideas of how to speed things up. The Minister wanted to see a significant increase in the number of claims processed for the registered infected cohort by June with numbers in the 1000's rather than the 100's. He also wanted all of the registered infected cohort to receive their compensation payments by the end of 2025 … the plans to significantly scale up by the end of the year had been explained to the Minister and he had requested a set of options around scaling up operations more quickly.*"[189]

In the light of this, and the forthcoming hearings of the Inquiry, "*The Board was asked to consider whether there were things that could be done or should be done to speed up delivery and would their view change if there was a genuine relaxation of the obligation to protect public money and take more risk.*"[190] After discussion, the next steps were recorded in the minutes as being:

> "*The overall plan would be to increase claims significantly by the end of the year and complete in the region of 500 claims by the end of June. It was agreed that the Chair would sign off the proposal.*
>
> *Arrange a meeting with the Minister to discuss the proposal and to ascertain what he could do to help with a clear ask for him to take on Ministerial risk.*
>
> *Come back to the Board for a decision(s) based on the outcome of discussions from Ministers.*"[191]

Sir Robert Francis and David Foley met the Minister and Permanent Secretary again on 30 April and the IBCA Board minutes of 1 May recorded:

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[187] IBCA Framework Document March 2025 para 15.9 WITN7755002

[188] IBCA Framework Document March 2025 para 16.6 WITN7755002. Annex A to the framework document sets out a range of "*guidance, documents and instructions*" that IBCA is required to comply with, which are all public documents and not specifically written for IBCA, including the Code of Conduct for Board Members of Public Bodies, the HM Treasury Guidance *Managing Public Money* and Freedom of Information Act guidance and instructions.

[189] IBCA Board Minutes 7 April 2025 paras 2.1-2.2 IBCA0000016

[190] IBCA Board Minutes 7 April 2025 para 2.6 IBCA0000016. The reference to the Minister and the Chair and CEO of IBCA being called to give evidence on 7 and 8 May is at para 2.4.

[191] IBCA Board Minutes 7 April 2025 paras 3.22-3.24 IBCA0000016

> "*The package of proposals for faster delivery that had been presented by the IBCA Executive was colour-coded to highlight the levels of risk that the Minister would need to underwrite for them to move ahead. The Minister expressed support for the green and amber-rated proposals and agreed with the Executive that the red proposals should not move forward.*
>
> *The discussion with* [the Minister for the Cabinet Office and Cabinet Office Permanent Secretary] *had focused on what could be achieved by the end of the year, provided certain conditions outlined in the proposals were met and there was support from Cabinet Office to release IBCA from some of its obligations via Ministerial direction.*
>
> *If the outlined conditions were met, IBCA was confident that it could deal with claims from all of the living registered infected cohort, some of the unregistered living infected cohort, and start on the affected cohort before the end of the calendar year, all by continuing our test and learn approach.*
>
> *IBCA had been clear that claims for estates could not start until 2026 and that prioritising the living infected would mean a slower process for the affected cohort. This would also mean that work on the supplementary route could not be started until next year.*"[192]

This matches what Nick Thomas-Symonds told the Inquiry about his role as the Minister responsible for IBCA as an Arm's Length Body:

> "*I still see my role in two senses. Firstly, to hold IBCA to account on the speed of payments because whilst there is that operational independence, I will nonetheless quite rightly be the minister held to account by Parliament for the speed of the payments quite rightly. That's how our democracy works … The second point is whilst of course recognising IBCA's operational independence to also be on hand to provide what is required.*"[193]

The Cabinet Office's Public Bodies Handbook provides guidance on the classification of public bodies. It states that Arm's Length Bodies ("ALBs") are "*a specific category of public body*" which include Executive Agencies, Non Departmental Public Bodies and Non Ministerial Departments. An Executive Agency is described as a public body that acts as an arm of its home department; a Non Departmental Public Body ("NDPB") is "*a public body that operates separately from its sponsoring department*"; and a Non Ministerial Department is "*a public body that shares many characteristics with a full department, but without a minister and acts separately from any sponsoring department.*"[194] An NDPB has "*a role in the process of national government*" but is "*not part of a government department.*" NDPBs operate "*at arm's length from ministers, though a minister will be responsible to*

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[192] IBCA Board Minutes 1 May 2025 paras 2.2-2.5 IBCA0000018

[193] Nick Thomas-Symonds Transcript 7 May 2025 pp124-126 INQY1000283

[194] Public Bodies Handbook Part 1 Classification of Public Bodies: Guidance for Departments p5, p8 RLIT0002956

Parliament for the NDPBs." The characteristics of an NDPB include: "*Dept. usually sets strategic framework, minister accountable to Parliament*"; "*Established and sponsored by Dept. with own separate legal personality, outside of the Crown*"; and staffing by "*public servants*" rather than civil servants.[195]

Both the Cabinet Office and IBCA say that IBCA **is** an Arm's Length Body (an NDPB). James Quinault states that IBCA has been set up by the Act to have "*the operational freedom to make the necessary decisions to deliver compensation*" in line with the Regulations, and that "*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 have, he says, "*no say in the decisions IBCA makes on claims or in any reviews of decisions on claims.*"[196] Sir Robert Francis observes that Parliament has set up IBCA as an independent Arm's Length Body and that he has been "*personally assured by the Minister and the Permanent Secretary that they regard the Authority as being operationally independent.*"[197] David Foley explains that it is for IBCA to make the decisions on individual claims, determining whether a person is eligible under the Regulations, determining the amount of compensation in accordance with the Regulations, and making the payments.[198] In broad terms, he describes the Cabinet Office as responsible for setting the policy framework of the legislation, which IBCA "*is then responsible for administering with full operational independence and accountability.*"[199]

I accept that IBCA is an Arm's Length Body in the sense described above. This is because it exists as a public body (an NDPB) in its own right under the Victims and Prisoners Act. It has the specific functions conferred on it under the Regulations of determining eligibility, calculating compensation and making payments in individual cases (as Sir Robert put it, "*in terms of paying money to people who are entitled under the scheme is concerned we would have operational independence and accountability in relation to how we went about doing that and, of course, in relation to individual decisions*"[200]). I have no reason to believe that ministers and civil servants[201] are involved in decision-making on individual cases. The IBCA Board minutes show the Minister acting on public and Parliamentary concerns, coupled with the knowledge that his own position whilst in opposition had been that speed of compensation was of vital importance, and seeking to speed up the delivery of compensation through IBCA as an ALB.

However, there are widely held and understandable concerns that:

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[195] Public Bodies Handbook Part 1 Classification of Public Bodies: Guidance for Departments p13 RLIT0002956

[196] First Written Statement of James Quinault paras 58-61 WITN7755001

[197] Letter from Sir Robert Francis to Sir Brian Langstaff 10 December 2024 p3 SRFS0000021

[198] First Written Statement of David Foley paras 18 and 20 WITN7757001

[199] First Written Statement of David Foley para 19 WITN7757001

[200] Sir Robert Francis Transcript 8 May 2025 p8 INQY1000284

[201] Though claim managers and staff of IBCA are still technically civil servants they are not discharging their former duties as civil servants, but are expected to act as if employees of IBCA until their position is regularised as such, in the way David Foley described (see the text above).

> "*IBCA is not an Arm's Length Body ("ALB") as all decisions on eligibility criteria and Tariffs and appeals lie with the cabinet office, that there has been no meaningful engagement with the community so as to influence the shaping of the scheme.*
>
> *…*
>
> *I am concerned that IBCA is not 'arm's length'. Everything about IBCA seems to me to be determined by civil servants (and thus, the Government). It seems to me that IBCA is an agent of the Government. This was the concern and issue victims had with the Skipton Fund. On the 27th November 2024 at the meeting of what is called the IBCA Communications Advisory Panel, we were told that all decision making rested with the Cabinet Office.*"[202]

Many do not trust IBCA's independence:

> "*There is a lack of trust as the IBCA say that they are an Arm's Length Body, but also say they have to report back to the Cabinet Office.*"[203]

Mary Grindley, an independent campaigner who has been campaigning for 45 years, suggested a reason for this:

> "*All of the individuals involved in the Infected Blood Compensation Authority are Cabinet Office staff and Civil Servants. To victims, these are the very same people who are responsible for the cover up of the infected blood scandal over decades and the appalling treatment of victims, evidence of which was heard in abundance by the Inquiry. Victims of contaminated blood should not be dictated to by the Cabinet Office.*"[204]

Some felt that the relationship between the prescriptive rules set by the Government and the way IBCA functioned meant that they had little say in the processes:

> "*While we were at the heart of the Inquiry, it feels like we are an afterthought and are now spectators in the process …*"[205]

These concerns reflect the fact that the compensation scheme was designed and structured by the Government and not by IBCA; that the tariffs and bands were devised and set by the Government and not by IBCA; that little discretion has been conferred on IBCA by the Regulations; and that IBCA's role is (essentially) to apply the rules devised by Government and set out in the Regulations to the individual claims. In other words, IBCA's role has been heavily circumscribed by the decision to reject the recommendation in the Second Interim Report to have a scheme completely independent of Government.

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[202] Second Written Statement of Lynne Kelly para 15, para 55 WITN3988094

[203] Fourth Written Statement of Sean Cavens para 12 WITN1146047

[204] Second Written Statement of Mary Grindley para 23 WITN2336029

[205] Fourth Written Statement of Sean Cavens para 11 WITN1146047

Put another way, IBCA is not the kind of independent and autonomous body that was envisaged in the Second Interim Report. Rather it is a body that technically fulfils the definition of an Arm's Length Body but which must operate within the powers of delivery conferred on it by the Victims and Prisoners Act. It was of course legitimate for the Government to have decided to structure the scheme in a way which it considered would better protect public money. However, its decision to reject the creation of a fully independent ALB still left it open for the Government, and then IBCA, to involve people infected and affected more closely in the creative design of the compensation scheme and how it would operate in practice.

IBCA must always be mindful of its independence, and this is especially so because the reason why first Sir Robert Francis in his Compensation Study, and second the Inquiry in its Second Interim Report recommended that an ALB be set up was because the people the body was to serve had lost trust in government. That is why the extent to which IBCA appears to have consulted or deferred to the Government has caused concern amongst people infected and affected.

In light of the fact that IBCA has been set up in the way described above, with more limited powers and functions than envisaged in the Inquiry's Second Interim Report, it is all the more important that IBCA and the Cabinet Office act both transparently and in a way that promotes IBCA's "*operational independence*". The following evidence suggests that the Cabinet Office is exerting (or did exert) an influence over the way in which IBCA exercises its functions in a way which leads to legitimate questions about that operational independence.

First, the Inquiry has been told that on numerous occasions IBCA is unable to answer questions and defers to the Cabinet Office. Nicola Leahey, an unrepresented core participant who made an oral closing statement to the Inquiry in 2023, states that "*When I have asked questions in the IBCA meetings they often reply that they need to ask the Cabinet Office.*"[206] Andrew Evans, although considering that IBCA has "*actively listened to us*", states that "*many of their answers to our concerns can be summarised by a deference to the policy team at the Cabinet Office*".[207] As described in a statement from the Scottish Infected Blood Forum, "*IBCA's hands are tied by its remit from Cabinet Office and decision-making with them is limited to operational matters of the compensation scheme, which has been designed and managed by Cabinet Office officials. To that extent it is not a true Arms-Length Body in the spirit of the Inquiry's report.*"[208] Michael Imperato of Watkins & Gunn states: "*my impression throughout, has been that the operational process has been driven as much by the Government (effectively the civil servants tasked accordingly) as IBCA. Indeed, at the various meetings I have attended with IBCA, discussions have often been led by Cabinet Office officials including matters of operation. This feeling, that IBCA is not truly 'arms-length', has been raised forcibly by way of concern by several of my clients.*"[209]

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[206] Third Written Statement of Nicola Leahey para 4 WITN0223015

[207] Fourth Written Statement of Andrew Evans para 11 WITN1213015

[208] Second Written Statement of the Scottish Infected Blood Forum para 19 WITN7165016

[209] Written Statement of Michael Imperato para 58 WITN7761001

Second, it is apparent that there have been extensive discussions between IBCA and the Cabinet Office regarding the interpretation of the Regulations. A Lessons Learned document recently produced by IBCA following its "test and learn" phase[210] records:

> "*We've been able to work with the Cabinet Office policy team to ensure that we understand in depth the policy intent behind each regulation – and from the perspective of operationalising them. This has enabled us to be clear on what is within IBCA's power to define and what is not and where it is the latter get more detail on intent so we are able to explain this where possible whilst still being clear that is regulations and not IBCA policy.*"[211]

David Foley told the Inquiry that:

> "*Where there is an interpretation about the regulations, we are always interested in being able to interpret it properly and understanding what the Government's intent in the regulation were and that does mean that we work in a multidisciplinary team on those issues. There's usually somebody from the Cabinet Office, if they feel they need legal advice they will get that from the Government Legal Department advice. There will be IBCA policy officials and there will be IBCA operational officials and where we have something that defines how they should be interpreted or is the key part about interpreting them, we will convey that as an explanation for why that has been the decision.*"[212]

James Quinault's written statement to the Inquiry explains that the Cabinet Office "*has provided extensive advice to IBCA on the development and interpretation of the Regulations, on both specific regulations, and on the Regulations taken as a whole.*" This has included "*explaining to IBCA the intended operation of particular regulations that are complex and would benefit from explanation*" and "*answering ad hoc queries from IBCA on the intended operation of regulations. This could involve 'sense checking' IBCA's interpretation in order to test whether it aligned with the intention behind the Regulations, providing advice on ambiguities, or seeking to outline the broader policy intention behind a particular regulation.*"[213]

Thirdly, the minutes of IBCA's Policy Forum show IBCA officials taking advice from the Cabinet Office Legal Advisers. At the Forum's meeting on 21 March 2025, the minutes record that "*AF would produce a paper on HIV infection dating to go to ExCo. This would be based on the contents of the dating principles paper, but informed by further advice to come from COLA* [Cabinet Office Legal Advisers] *by 28th March 2025. AF to commission*

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[210] IBCA began with a "test and learn" approach. Such an approach aims actively to test approaches on a small scale, improving them as they are developed and then scaling up with confidence. David Foley told the Inquiry "*although you start small, you are then able to accelerate and go faster because you have built a system that works for the real world, for the people who are using it*." David Foley Transcript 8 May 2025 p24 INQY1000284

[211] IBCA Lessons Learned from early compensation claims 2 May 2025 para 1b WITN7757020

[212] David Foley Transcript 8 May 2025 p83 INQY1000284

[213] Third Written Statement of James Quinault paras 6-7 WITN7755006

that advice from COLA."[214] The minutes of the following meeting, on 22 April 2025, record that "*Audree Fletcher talked the group through the HIV dating paper that had been pulled together after legal advisors had given their opinion on IBCA's current approach.*"[215]

James Quinault correctly points out that IBCA has the discretion to take a different interpretation from that offered by the Cabinet Office. I accept that, as he also says, the Cabinet Office "*does not provide IBCA with guidance or instructions on what decisions to take in regard to individual claims.*"[216] Nonetheless, it is clear that when IBCA forms a view on the interpretation of the Regulations or on the way to approach issues within the Regulations, which is based on, or has been heavily influenced by Cabinet Office input and advice, that will inevitably impact upon the decisions that are then taken by IBCA with regard to individual claims.

The written submissions on behalf of those represented by Milners Solicitors rightly characterise the position revealed by this evidence as concerning.[217] I agree with them that the Cabinet Office's view of what a statutory instrument passed by Parliament means carries (or should carry) no greater weight than the interpretation applied by an applicant to the scheme, and that it is inappropriate for IBCA to consult **solely** with, and take advice only from, the Cabinet Office. To do so is indicative of a lack of independence and autonomy on the part of IBCA, and is unfair, being one-sided. IBCA should form its views on matters relating to the interpretation and application of the scheme both having taken its own independent legal advice and in the light of collaboration with the lawyers who are representing applicants.

The Inquiry has heard nothing to suggest that input has actively been sought from sources independent of the Cabinet Office, though David Foley has told the Inquiry a Clinical Panel will be established "*which will provide independent expert advice on the interpretation of the Regulations and on the formulation of operational policy in administering the compensation scheme.*"[218]

Where any advice which IBCA receives (from the Cabinet Office or elsewhere) affects the entitlement of an individual, it should be made available to them.[219]

The fact that IBCA's senior leadership team is entirely comprised of people who were (prior to taking up their positions on an interim basis) senior civil servants, and the fact that the staff working within IBCA are currently still civil servants has been unhelpful to IBCA in answering general criticisms about its independence. Staffing IBCA when it first began by

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[214] IBCA Policy Forum Minutes 21 March 2025 WITN7757014

[215] IBCA Policy Forum Minutes 22 April 2025 WITN7757015

[216] Third Written Statement of James Quinault para 9 WITN7755006

[217] Written Submissions on behalf of the core participants represented by Milners Solicitors paras 93-99 SUBS0000086

[218] Fifth Written Statement of David Foley para 17 WITN7757022

[219] Subject, as is necessary and usual, to whether the document is privileged against production, as in the case of legal professional privilege, though it must be understood that privilege in any advice to IBCA is for IBCA to waive, and transparency suggests that, absent good reason not to, it should do so.

seconding or recruiting from within the Civil Service was almost inevitable if it was to be up and running within a short timescale. However, it has given rise to a scepticism about their true independence which might have been dispelled if there had been greater engagement and openness about the necessity of their appointment at the start of the operation. The evidence from David Foley that he expects that by October this year the staff will become direct employees of IBCA is welcome. IBCA should ensure that people infected and affected are updated about the progress which it is making in this regard.

I have described in some detail above IBCA's structure, its status, its functions and its powers, precisely because there has been, and continues to be, so much understandable concern, confusion and suspicion regarding IBCA and its relationship with the Government. That concern, confusion and suspicion resulted from the Government's decision (which it has explained was because of the need for stewardship of public money) not to create a fully independent compensation body accountable directly to Parliament, but instead to design for itself the structure of the compensation scheme, setting the levels for awards, and to confer upon IBCA the more limited role of administering the scheme. However that role, although limited, is nonetheless of considerable importance. Whilst the way in which IBCA has been established inevitably entails a formal and continuing relationship between IBCA and the Cabinet Office, it is therefore all the more important that IBCA should be, and be seen to be, fair, impartial, and transparent in its policies, practices and decision-making, and equally important that it should ensure the involvement of people infected and affected in all that it does. It is to this question of involvement that I now turn.

Securing the involvement of people infected and affected

It was the recommendation of the Inquiry in its Second Interim Report that there should be an advisory board of the compensation body, which should include beneficiaries ("*it is important that decisions about those who should receive compensation are not made without them*").[220] Further, it was a recommendation of the Inquiry that "*those set to benefit from the scheme (people infected and affected) must have a central influence on its decision-making and operation*".[221]

As described earlier in this Additional Report, the Government has made decisions without the involvement of people infected and affected, who were not given the opportunity to have a significant (still less central) influence on the design and content of the compensation scheme.

IBCA has held meetings with people infected and affected and has sought to engage in different ways.[222] David Foley reiterated in his written statement a commitment "*to the involvement of people infected and affected by the use of infected blood in IBCA's decision-*

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[220] Infected Blood Inquiry Second Interim Report 5 April 2023 p19 INQY0000453

[221] Infected Blood Inquiry Second Interim Report 5 April 2023 p21 INQY0000453

[222] As described in the First Written Statement of David Foley para 11 WITN7757001. David Foley told the Inquiry that there had been over 175 meetings, either in person or online with either open invitations for everyone or groups of specific people. David Foley Transcript 8 May 2025 pp81-82 INQY1000284

making."[223] Sir Robert Francis emphasised his "*personal commitment and the organisation's commitment to involve the community in everything we do … what we are after is a two-way conversation about what we do.*"[224]

Some concerns have been voiced about the nature and extent of involvement and the nature and quality of the interactions that have taken place. For example, that "*They talked down to us, they were condescending, they had scripted answers for everything*";[225] "*I would describe attempts to communicate as like 'banging our heads against a wall' because the IBCA is quite happy to sit in a meeting with campaigners but they aren't actually listening to, or acting upon what we have to say*";[226] "*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*";[227] "*Genuine concerns have been brushed aside with vague or technical responses … To summarise, my experience has not been one of involvement but of being kept at arm's length.*"[228]

Other evidence suggests a willingness by IBCA to listen[229] but a limited ability to respond:

> "*The IBCA staff do engage more than the CO, but their hands seem tied. They are now trying to engage, albeit too late, and simply appear impotent, as they cannot provide any answers and say they cannot make any changes. That is of no use to the Community. What is the point of speaking with the Community if, as an organisation such as IBCA, you have no power to make any changes. The CO is simply deflecting to IBCA.*"[230]

However, although efforts have rightly been made by IBCA to meet and communicate with people infected and affected, what is fundamentally lacking is a formal, significant and influential role for people infected or affected within IBCA.[231] Such lack of involvement both exacerbates mistrust in IBCA and perpetuates the harm which people have suffered over decades. Furthermore, there has been little or no consultation with people infected and affected or their legal representatives about IBCA's policies and processes, so as to enable

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[223] First Written Statement of David Foley para 11 WITN7757001

[224] Sir Robert Francis Transcript 8 May 2025 p76 INQY1000284

[225] Alan Burgess Transcript 7 May 2025 Transcript p15 INQY1000283

[226] Second Written Statement of Stuart McLean para 5 WITN0653028

[227] Second Written Statement of Gary Webster para 21 WITN1723044

[228] Written Statement of Owen McLaughlin para 10 WITN7766001

[229] John Dearden of Haemophilia Scotland, for example, spoke positively about a meeting with IBCA on 18 January 2025 in Glasgow, explaining that "*A range of topics were covered with the IBCA undertaking to answer those questions where time prevented a full response. Members found this a useful experience where there was ample opportunity to engage over the two and a half hour session. We made a recording of the event available to those members who were unable to attend. The government could learn from such an inclusive approach rather than limiting representation.*" Written Statement of John Dearden on behalf of Haemophilia Scotland para 40 WITN7754001

[230] Third Written Statement of Samantha May para 43 WITN0912009.

[231] Other than through the appointment of three user consultants, whose roles are limited: they are not involved in decision-making or governance. The appointment of user consultants has generated some controversy, in part no doubt because of their limited role, and because the appointment of a very small number of individuals (whoever, and however knowledgeable, they might be) cannot be a substitute for the wider involvement of people infected and affected.

them to have a formative and central role in them. Indeed, as set out later in this chapter, such policies and processes have for the most part not even been made public.

There is a proposal to establish an advisory board comprising people infected and affected. David Foley told the Inquiry that the IBCA Board has been "*finalising its arrangements about how it would like that to be built.*" He referred to the challenge of ensuring "*that it is a fair spread of people from across all of the community, that everybody has a fair opportunity to say that they would like to be on it and also that it's very clear to everybody how it functions and what it does.*" His "*hope*" was that the approach could be agreed at the next Board meeting.[232] This is important, but should have happened much sooner and no good reason has been advanced for the delay. The need for it was recognised by Sir Robert Francis back in May 2024, when he identified as one of the principles that should inform the work of IBCA "*From now on*" the involvement of "*the infected and affected communities in the important decisions made about the scheme*".[233]

Concerns about uninformative responses by IBCA to suggestions made by people infected and affected, or expressing a sense that contributors had not been listened to, led to this exchange in the evidence:

> "*Q: it may be helpful to have a clear communication when issues have been raised … this is our response to it ... Or, this has been raised with us - saying clearly, so everybody understands, because this is such a difficult scheme to understand: this is not something we can change, these are the rules we're bound by, we have forwarded this to the Cabinet Office or: we've listened, we understand, but we are not going to do it for these reasons*
>
> SIR ROBERT FRANCIS: *The principle of what you say is absolutely right and I would like to think that's what we're endeavouring to do …*
>
> DAVID FOLEY: *... We welcome all suggestions about how we can do it better.*"[234]

Some witnesses have expressed concerns regarding aspects of IBCA's communications, including in relation to their clarity and tone. There has on occasion been some insensitivity in the choice of language, which does not help in rebuilding confidence and trust.

The use of the words "*invite*" or "*invitation*" to describe the approach to people to begin their compensation claims has been criticised. Sir Robert in his oral evidence on 8 May 2025 addressed this directly, saying "*Can we apologise for the use of the expression because we've taken that on board and we no longer use that ourselves and I hope that's going to begin to percolate through to the correspondence.*"[235] It is not necessary therefore to say anything further regarding the terminology of invitation.

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[232] David Foley Transcript 8 May 2025 p17 INQY1000284. As noted earlier in the Additional Report, IBCA has the statutory power to appoint such a body, and may set its procedure.

[233] Sir Robert Francis's Statement of Intent 29 May 2024 WITN7757009

[234] Sir Robert Francis and David Foley Transcript 8 May 2025 pp79-80 INQY1000284

[235] Sir Robert Francis Transcript 8 May 2025 p63 INQY1000284. IBCA announced on 14 May 2025 that they would henceforward remove the term "*invited*" from correspondence.

Ben Harrison of Milners Solicitors observed that:

> "*The updates which the IBCA provides to campaigners can be rather dense and, as I have said previously, impenetrable to a number of infected and affected people who contact me for interpretation. I have some sympathy for the IBCA in this regard because many of the updates, particularly those concerning the Regulations, are attempting to convey extremely complicated information which I can appreciate may be difficult to simplify to the requisite extent. However, many of the IBCA's written communications often appear tone-deaf. A prime example is the regular updates that the IBCA has provided since December about the number of claims which have been invited, the number of offers of compensation which have been made and the total amount which has been paid out. Some of my clients have reported to me that they perceive these updates as self-congratulatory in tone which they consider to be wildly inappropriate given the lack of any apparent significant increase in the rate at which claims are being accepted by the IBCA.*"[236]

The Scottish Infected Blood Forum, Contaminated Blood Campaign and others observe that:

> "*There needs to be more considerate use of language, particularly because these* "*words matter*" *because of the subject, and particularly when they are part of what appears to be the latest line to take. One current example is the use of* "*life-changing*" *to describe the anticipated amounts of infected blood compensation as if it applies to everyone. It is perhaps ironic that the same phrase,* "*life-changing*"*, is used by the Police to describe the more serious end of the spectrum of injuries that a victim of crime has sustained … It was the infections that were life changing. In the attempted flip to positive, life-changing sounds more like a sound-bite spin phrase to pitch to an undiscerning media short on background fact checking. It has become an unwelcome and unhelpful trope that is akin to the previous disingenuous phrase, or lie,* "*working at pace.*"[237]

The written submissions on behalf of the core participants represented by Collins Solicitors ask that IBCA desist from referring to estate claims as affected and instead ask that IBCA refer to "infected deceased claims", noting that:

> "*Although this would mean that IBCA would not use the phrasing of the Regulations, it would require no legal change and would mean a great deal to the community. Had effective consultation been carried out to date, this linguistic change would already have occurred. It requires merely an empathetic change of practice and a sense of the strength of the feeling in the community.*"[238]

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[236] Written Statement of Ben Harrison paras 83-85 WITN7759001

[237] Infected Blood Compensation: Getting It Right November 2024 pp24-25 WITN7165021. The Inquiry checked: the term has been used by IBCA or the Government on at least seven occasions between August 2024 and February 2025 when describing the sums payable in compensation.

[238] Written Submissions on behalf of the core participants represented by Collins Solicitors para 109 SUBS0000092

If there is greater involvement of, and consultation with, people infected and affected – an issue which I will return to in the chapter on *Recommendations* of this Additional Report – I would expect both that IBCA would swiftly be alerted to any insensitive usage of language or unduly complex wording, and that it would ensure that it was avoided.

Transparency

It is fundamental, both to good governance and to gaining the trust of the people for whose benefit the scheme exists, that there be transparency about what IBCA is doing and why. This is why the Second Interim Report recommended that "*the processes of the scheme need to be as transparent as legally possible*".[239]

Sir Robert rightly identified transparency as one of the values that IBCA should work to in his statement of intent in May 2024.[240] In his July 2024 report to the Government, Sir Robert recommended that a greater degree of transparency should be adopted, observing (in relation to IBCA) that "*IBCA will undertake to be transparent in its decision-making in setting up the processes by which applications will be received and assessed, and awards made, and will set up mechanisms for ensuring that this is informed by the involvement of the infected and affected communities in their production.*"[241] Transparency is identified on IBCA's website as one of the "*7 simple principles*" that IBCA works to.[242] To date, however, IBCA has not lived up to this principle. Some examples follow.

The important role played by clinical assessors in IBCA's decision-making[243] has only become apparent through the evidence gathered for the Inquiry's hearings on 7 and 8 May 2025. There have been no references to clinical assessors, or descriptions of their role, in any of IBCA's newsletters and community updates.[244] There have been no descriptions of the role of clinical assessors on IBCA's website, which has been operational since 9 December 2024. This is not transparency.

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[239] Infected Blood Inquiry Second Interim Report 5 April 2023 p21 INQY0000453

[240] Sir Robert Francis's Statement of Intent 29 May 2024 WITN7757009

[241] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p15 RLIT0002466

[242] IBCA website About us RLIT0002959. In a letter from Sir Robert Francis KC of 10 December 2024 he emphasised this again: "*I fully endorse your remarks on the importance of transparency and candour. I have made it clear from the outset, with the full support of our Chief Executive, that we expect the Authority to operate entirely consistently with those principles. Indeed, I do see the setting up of this Authority as being a real opportunity to demonstrate a different way of providing a public service*." Letter from Sir Robert Francis KC to Sir Brian Langstaff 10 December 2024 p5 SRFS0000021

[243] The role of clinical assessors is discussed further below.

[244] The clinical assessor role was referred to in a letter from David Foley to legal representatives on 17 January 2025, but this simply referred to a claim manager seeking clinical assessor input where appropriate and the possibility of cases being referred to a clinical assessor for an expert opinion on changes in infection severity. Letter from David Foley to legal representatives 17 January 2025 WITN7763019. The first reference to a clinical assessor in IBCA's community updates appears in its 14 May 2025 update, which merely states that IBCA intends to refer to "*clinical advisors*" rather than "*clinical assessors*". IBCA Community Update 14 May 2025 p4 RLIT0002970

None of the guidance, advice or instructions to claim managers – who are, as David Foley has explained in his witness statement, the people "*empowered to make decisions on individual claims*"[245] – has been published by IBCA.[246] This is not transparency.

None of the work undertaken by IBCA with the Cabinet Office's policy team to ensure that IBCA understands "*in depth the policy intent behind each regulation*"[247] has been published by IBCA.[248]

None of the papers that have been produced by IBCA addressing specific issues within the Regulations – such as the "dating principles paper", the "paper on HIV infection dating" and the "Hepatitis B (post-1972) paper"[249] – has been published by IBCA.

Nothing regarding IBCA's approach to the Hepatitis severity bandings in Schedule 1 to the 2025 Regulations – which can make a critical difference to the amount of compensation payable to an individual infected with Hepatitis – has been published by IBCA, despite there being evidence that IBCA's policy team has advised that a diagnosis of cirrhosis is needed in order to meet the Level 3 criteria.[250]

None of the minutes of the meetings of IBCA's Board has been published by IBCA.

None of this provides transparency. Transparency really matters. It was identified by Lord Nolan when setting out the seven principles of Public Life as one of those principles for a reason: it accords with people's sense of justice that they be told, in ways they can understand, how a decision relating to them will be made and why, when it is made, it is made as it is. In the history of infected blood the way in which the Macfarlane Trust operated gives just one example of how much a failure can affect people. The effects of a lack of information, and a lack of transparency, which were demonstrated in respect of infected blood are chronicled there.[251] But where a similar lack of transparency is repeated,

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[245] First Written Statement of David Foley para 20 WITN7757001

[246] See for example IBCA Claim Managers' Playbook May 2025 IBCA0000001, IBCA Key determinations May 2025 IBCA0000002. These undoubtedly should have been published.

[247] IBCA Lessons Learned from early compensation claims 2 May 2025 WITN7757020

[248] I record this as a matter of fact. Sir Robert Francis noted that "*in my recommendations I made after the engagement in June and July, a lot of them were about encouraging the Government to explain the reasons for -- lying behind the various contentious policies … you need to distinguish between … relayed, reported Government view and … how we're going to apply those regulations because they can and probably usually are two different things.*" Sir Robert Francis Transcript 8 May 2025 pp84-85 INQY1000284 David Foley told the Inquiry: "*IBCA does not consider that it is part of its role to publish any understanding of the 'policy intent' behind each regulation. It may be that this is something which the Cabinet Office will do.*" Fifth Written Statement of David Foley para 8 WITN7757022. If, however, IBCA's understanding of the policy intent behind each regulation is shaping or informing its approach to the assessment of compensation in individual cases, then that understanding should be made public – whether by the Cabinet Office, or IBCA, or both.

[249] IBCA Policy Forum Minutes 21 March 2025 p1 WITN7757014, IBCA Policy Forum Minutes 22 April 2025 WITN7757015. IBCA Draft paper for discussion *Date Treatment* March 2025 IBCA0000005, IBCA Draft paper for discussion *HIV eligibility* April 2025 IBCA0000005, IBCA Draft paper for discussion *Determining Hep B eligibility* April 2025 IBCA0000007, IBCA Draft ExCo paper *Hep B eligibility determinations after 1972* April 2025 IBCA0000008

[250] The correctness of this approach is considered later in this Additional Report.

[251] See Volume 6 of the Inquiry Report, where the lack of transparency of the Macfarlane Trust is set out, and its effects as one cause of a lack of confidence in that Trust are demonstrated. Infected Blood Inquiry

in respect of the recipients of infected blood, by another body set up with the intention of benefiting people, this is no longer a question of history but an example of a failure to learn from it. For instance, and as the submissions made to the Inquiry in respect of the Additional Report point out, people are entitled to know how, by whom, and why decisions in individual cases have been reached.[252] Transparency is vital if mistakes or misunderstandings are to be corrected.[253]

IBCA has suggested that publication of internal guidance is unnecessary "*where assistance can be given directly to any who require it and publication poses an unacceptable risk of impacting IBCA's work through the increase in fraudulent claims and their sophistication.*"[254]

This is unsatisfactory. It requires an individual who has already been subjected for decades to a lack of candour and transparency, lines to take, and institutional defensiveness, to trust the interpretation of the Regulations contained within that guidance given by the IBCA and in the knowledge that IBCA has consulted extensively with the Cabinet Office, without being able to see the guidance itself or understand how the interpretation is formulated. There is no sufficient explanation how the publication of such guidance could, of itself, increase the risk of fraud.[255] Though the risks of fraud clearly require protective measures, there

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Report 20 May 2024 Volume 6 pp59-129 INQY0001006

[252] Thompsons Solicitors (Scotland) submit on behalf of the core participants they represent that there should be such transparency. Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) paras 2.74 - 2.75 SUBS0000084. Leigh Day on behalf of the core participants they represent submit that individuals must be able to understand how decisions are made and to expect consistency in how claims are treated. Written Submissions on behalf of the core participants represented by Leigh Day para 16 SUBS0000088. Watkins & Gunn submit on behalf of the core participants they represent that medical assessments and all information which is taken into consideration by IBCA must be shared with the individual and that reasons for decisions must be provided, as a minimum requirement of basic fairness. Written Submissions on behalf of the core participants represented by Watkins & Gunn para 14 SUBS0000091

[253] One example, from the Claims Managers Playbook reads "*The end dates for Hep B, Hep C and HIV windows are the dates routine screening was introduced in the UK - the point after which being given infected blood became improbable. These years are 1972, 1991.* [1985 for HIV]" IBCA Claim Managers' Playbook May 2025 p5 IBCA0000001. It is entirely wrong, for example, to suggest that infection with Hepatitis B was improbable after 1972 – the evidence, in the Inquiry Report, is clear (a) that the screening test introduced in 1972 picked up less than half the donations which contained infective particles; and it was some 10 years later before screening tests had improved so as to identify all but a few infected donations (b) the risks of transmission of Hepatitis B through the use of blood products remained a risk well into the 1980s where blood products were imported. Infected Blood Inquiry Report May 2024 Volume 3 p5, p57, p457, p474 INQY0001003. Further, the use of the word "improbable" determines the burden of proof – the evidence about effective screening tests is certainly a matter to be taken into account, but cannot be regarded as conclusive. There is a balance to be struck on all the evidence, not just one feature of it as this suggests. If this Playbook had been published, these matters would have been open to correction.

[254] Third Written Statement of David Foley para 11 WITN7757011

[255] Milners Solicitors comment in their clients' submissions to the Inquiry that: "*We do not understand Mr Foley's fears or how the publication of guidance could lead to an increased risk of fraud. If the fear is that someone might fraudulently produce documents to enhance their claim, then they are just as likely to do that at whatever point they become aware of the Scheme's requirements …*" I share this view. They give a cogent example: "*The prime example of where policy uncertainty for Scheme applicants is causing difficulties is with the interpretation of Schedule 1 of the Regulations and particularly, how the IBCA is interpreting the definition of cirrhosis. The IBCA has clearly prepared some fixed parameters for what they will accept, without further evidence, as an eligibility for level three entitlement. Scheme applicants should know what those parameters are and should have an understanding of how they came to be set. Without this information, Scheme applicants do not have sufficient information to challenge the interpretation of the Regulations which the IBCA is employing.*" Further, they add that as a matter of

is no good reason why a lack of transparency as to internal guidance, policies and other important material should be one of them.

It should be noted, too, that the provisions of the Public Bodies (Admission to Meetings) Act 1960 apply to IBCA.[256] This provides that meetings of the Authority are to be open to the public,[257] with (in general) at least 3 days' notice being given.[258]

I recommend at the conclusion of this Additional Report that transparency should be adopted in the processes of IBCA. It has been lacking up to now.

The role of clinical assessors

As recorded above, it has become increasingly apparent that the clinical assessors[259] may play an important role in the determination of compensation claims. David Foley explained that clinical assessors "*play a very important function in our organisation … there are decisions that have to be made that require clinical expertise in particular, for example, thinking about the degree of severity of fibrosis and that would be an example of where a clinical assessor would provide some expert advice that a claims manager simply wouldn't have.*"[260]

As at 8 May 2025 there was one clinical assessor.[261] David Foley was not aware of that individual's experience and expertise when he gave oral evidence, but has subsequently provided a statement which records that the assessor has substantial experience in treating infectious diseases with a specialism in HIV and in travel and tropical illnesses, and has spent many years working in Hepatitis B and Hepatitis C clinics. She has also been a medical assessor for EIBSS since 2020.

Although the assessor has experience in Hepatitis, it does not appear that she is an hepatologist. She typically works 2-3 hours per week providing direct support on claims, with the claim manager providing the clinical assessor with "*an anonymised synopsis of the case and the information to be considered.*"[262] Such limited availability – one clinical assessor, for 2-3 hours per week – may have been a factor in the slow rate of progress with respect to claims.

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fact "*IBCA has not consulted with community groups or legal representatives on any policy or guidance which concerns the material interpretation of Regulations.*" Written Submissions on behalf of the core participants represented by Milners Solicitors para 142, para 141c SUBS0000086

[256] Schedule 1(r) to the Public Bodies (Admission to Meetings) Act 1960 RLIT0002971

[257] Subject to safeguards which are set out in the Act

[258] Section 1(4) of the Public Bodies (Admission to Meetings) Act 1960 RLIT0002971. This also provides for agendas to be available on request, subject to appropriate charges (s.1(4)(b), along with copies of reports or other documents supplied to members in connection with the relevant agenda item.

[259] IBCA has recently decided to refer to "*clinical advisors*" rather than "*clinical assessors*" but as most of the evidence considered by the Inquiry used the term "*clinical assessors*" that is the description used in this Additional Report. IBCA Community Update 14 May 2025 p4 RLIT0002970

[260] David Foley Transcript 8 May 2025 p18 INQY1000284

[261] Clinical assessor was the term used in David Foley's Second Written Statement and is the term used in this Additional Report. His Third Written Statement uses the term clinical advisor. Second Written Statement of David Foley para 14 WITN7757010, Third Written Statement of David Foley para 1 WITN7757011

[262] Third Written Statement of David Foley para 2, para 5 WITN7757011

IBCA is now in the process of recruiting further clinical assessors. It has a contract with a healthcare resourcing company to provide their services. David Foley's statement of 20 May 2025 suggests that this contract is for the provision of approximately 10 clinical assessors, although the service specification exhibited to his statement requests the provision of 5-10 clinicians. The areas of expertise sought are haematology, hepatology, gastroenterology and general practice. Each clinical assessor is required to be available for approximately 2 hours per week initially, with potential for increased hours as IBCA expands.[263] In his fifth statement of 2 June 2025 David Foley confirmed that the additional clinical assessors are now in place.[264]

The clinical assessors may be asked to advise on a range of issues, including "*advice on the infection diagnosis; advice on the diagnosis date; advice on the likely infection context; and advice on the likely infection severity history.*"[265] Advice on these issues may determine whether a person is regarded as eligible or not and is likely to make a significant difference to the calculation of compensation. It is essential, therefore, that there is transparency about the advice of the clinical assessor; the factual basis on which that advice has been given;[266] and the reasons for that advice.[267] Such information must be shared with the individual in writing so that they, and where represented, their solicitor, can understand and where appropriate challenge the correctness of that advice. This is particularly important where medical records are missing or sparse, and where the clinical assessor is being asked for advice which will shape the claim manager's balance of probabilities assessment.

Given the evidence in respect of clinical assessors, and their importance, it is important that anyone asked to perform that role is fully aware of the standards which were in practice adopted at the time for any case they are asked to consider. They should be asked to make themselves aware of (or preferably be trained concerning) issues which may now be largely historical, but forty or so years ago were common, such as the overuse of blood, top-ups and the use of blood transfusions for new mothers following childbirth, and variable surgical

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[263] Third Written Statement of David Foley para 6 WITN7757011, Service Specification: Infected Blood Compensation Authority (IBCA) Clinical Advisors May 2025 WITN7757012

[264] Fifth Written Statement of David Foley para 12 WITN7757022

[265] Third Written Statement of David Foley para 7 WITN7757011

[266] David Foley explains that clinical assessors are provided "*with any information they require in order to make their assessment which includes any relevant sections of the medical records.*" Fifth Written Statement of David Foley para 14 WITN7757022. Whilst not over-burdening the clinical assessor with an individual's medical records may have an advantage on the ground of efficiency, this suggests that it is down to the claim manager (who has no clinical expertise) to identify the "*relevant sections*" of the medical records to put before the clinical assessor. This reinforces the importance of ensuring that the individual and (where represented) their lawyer is told what information has been provided to the clinical assessor.

[267] David Foley explains that the individual will receive "*a written record at the declaration stage of the information that will be used to calculate the claim and the basis for the decisions.*" Fifth Written Statement of David Foley para 16 WITN7757022. It is equally important however that the individual receives a written communication of any advice from the clinical assessor. IBCA's clinical advisors' briefing pack states that after a session with a claim manager, the clinical advisor "*must complete the written section of the decision form with their advice and reasoning. This written advice should be clear and defensible, as it will be saved as part of the claim record and could be scrutinised in any appeal or audit.*" Clinical Advisors' Briefing Pack - IBCA Programme 2025 p6 WITN7757023; Clinical Advice Record WITN7757024. It should therefore be straightforward for the clinical assessor's advice and reasoning to be shared with the individual whose eligibility and compensation are being assessed.

practice not only in giving transfusions but also in recording that a transfusion had been given. Unless clinical assessors have a real appreciation of the deficiencies and variabilities in the way that treatment was given at the time of any implicated transfusion or administration of blood product there is a very real risk that IBCA will continue to repeat mistakes of the past and mirror some of the decision-making by the former Alliance House Organisations and Infected Blood Support Schemes. There is evidence that when assessing applications on a balance of probabilities, those bodies often failed to consider adequately what the absence of medical evidence signified, or what would have occurred in practice during the individual's treatment period. If IBCA adopts the same approach, individuals may be denied compensation they ought to be receiving. In the specific case where there is a proper role for a clinical assessor deciding whether a fibrosis level is sufficient to qualify a person for a Level 3 award, that clinical assessor should be a specialist. Where there is a clinical assessor who is not specialist – for instance, is a general practitioner – there is a danger that they are likely to rely on textbook reference points to evaluate scan results or biochemical markers. This risks resulting in a flawed assessment of borderline cases. Moreover, if and to the extent that the extra-hepatic consequences of Hepatitis infection, and the after-effects of the treatments for it, are relevant to an award, it is important that the clinical assessor be a hepatologist familiar with these as well as having a good understanding of the likely psychological consequences of infection and, in particular, treatment.

David Foley describes the Clinical Panel that IBCA is setting up as "*a further source of expertise to ensure that the clinical elements of our work are of the highest standards, including, where needed any decisions of 'policy' on clinical matters*",[268] providing "*independent expert advice on the interpretation of the Regulations and on the formulation of operational policy in administering the compensation scheme.*"[269] Transparency and fairness requires that any such advice is shared with people infected and affected and with the legal representatives, for the reasons already set out above.

The role of legal representatives

Given both the complexity of the 2025 Regulations and the fundamental importance of ensuring that individuals receive the compensation which the Regulations entitle them to, it is obvious that legal support must be available (free of charge) to those individuals who want that support.

In his written statement to the Inquiry Nick Thomas-Symonds suggested that:

> "*The Infected Blood Compensation Scheme has been designed with the principle of accessibility in mind. The scheme is tariff-based, this means individuals do not need to provide a detailed account of losses. Therefore it is not expected that an individual would require legal support to apply. However,*

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[268] Third Written Statement of David Foley para 9 WITN7757011

[269] Fifth Written Statement of David Foley para 17 WITN7757022

> *I will continue to endorse the provision of support to applicants to the scheme where it is appropriate and in line with proper use of public funds.*"[270]

In his oral evidence, however, and in response to the suggestion from Counsel to the Inquiry that, given the nature of the Regulations, it was neither realistic or fair for an individual to be without legal support, he rightly accepted that "*That is why I have signed off both legal support and also financial advice as well, and that's what I had in mind.*"[271] The Minister agreed also that legal support should be available for supplemental route claims.[272]

Funding for legal support for core route claims has now been put in place, and as the Minister has agreed in principle that it should be available for supplemental route claims, it is not necessary for me to make a specific recommendation other than that it should continue to be available for as long as claims are continuing.

The importance of individuals having access to legal support is reinforced by the evidence the Inquiry has received from recognised legal representatives. Patrick McGuire of Thompsons Solicitors (Scotland) notes that "*The IBCA Regulations are highly technical and there have already been instances where Case Managers have misinterpreted them, leading to claimants receiving incorrect information.*"[273] Gene Matthews of Leigh Day reports that "*it has been reported to me that claims managers have in some instances provided the wrong information to individuals in relation to the operation* [of the Regulations]".[274] Danielle Holliday of Collins Solicitors explains that they have found the wrong dates of infection and/or diagnosis being used by claim managers, which would have (if unchecked) resulted in undercompensation.[275]

The Inquiry has received evidence from legal representatives who acted for individuals during the Inquiry, and continue to act for them in relation to the processing of compensation claims, which suggests that IBCA may not have welcomed the involvement of lawyers. Ben Harrison of Milners Solicitors, describing the position as in the summer of 2024, explains that "*it felt clearly to me as though our (the RLRs') input was not welcome by either the IBCA or Cabinet Office … The lack of engagement with RLRs struck me as incredible; between us, we knew and represented a vast number of infected and affected people – we were well placed to explain the implications of the Government's proposals to our clients but were unable to do so efficiently because of this lack of engagement.*"[276] Danielle Holliday of Collins Solicitors considers that the involvement of legal representatives "*was discouraged*" and describes "*a complete refusal or inability to engage with the RLRs who*

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[270] Written Statement of Nick Thomas-Symonds paras 78-81 WITN7753001

[271] Nick Thomas-Symonds Transcript 7 May 2025 p171 INQY1000283

[272] Nick Thomas-Symonds Transcript 7 May 2025 p187 INQY1000283

[273] Written Statement of Patrick McGuire para 36 WITN7760001

[274] Written Statement of Gene Matthews para 46 WITN7762001

[275] Written Statement of Danielle Holliday paras 80-94 WITN7763001

[276] Written Statement of Ben Harrison paras 11-12 WITN7759001. See also, in relation to later interactions with IBCA, paras 24-30.

have represented infected and affected people for years."[277] Gene Matthews of Leigh Day Solicitors "*felt that the IBCA did not really wish to engage with the RLRs*".[278] Patrick McGuire of Thompsons Solicitors (Scotland) refers to "*a perceived undermining of Legal Representation. There appears to be an implicit, if not explicit, position within IBCA that legal representation is unnecessary due to the availability of Case Managers.*" He points out, as do others, that the Regulations "*are highly technical, and there have already been instances where Case Managers have misinterpreted them, leading to claimants receiving incorrect information.*"[279] Michael Imperato has gained the impression from clients who have had direct interactions with IBCA that "*lawyers are portrayed by IBCA as something of a drag on the process, slowing it down, being too cautious, wanting to check through a client's records thoroughly.*"[280]

It is also unfortunate (to say the least) that during the process of agreeing the arrangements for lawyers to support individuals with the assessment of their compensation, a clause was proposed by IBCA which (if accepted) would have restricted the lawyers' ability to air criticisms in public – a so-called gagging clause.[281]

It may be that some of the apparent reluctance to involve legal representatives stems from past experience in relation to miners' compensation. Memories of what happened twenty years ago to the miners' community appeared still to be raw when Nick Thomas-Symonds spoke of the scandal in his evidence on 7 May.[282] I should be absolutely clear, however, that what happened then does not justify any reluctance there may have been to involve lawyers on behalf of their clients in this compensation scheme. In the present case, there have now

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[277] Written Statement of Danielle Holliday para 42, para 46 WITN7763001

[278] Written Statement of Gene Matthews para 25 WITN7762001

[279] Written Statement of Patrick McGuire paras 35-36 WITN7760001

[280] Written Statement of Michael Imperato para 45 WITN7761001

[281] Written Statement of Danielle Holliday paras 65-67 WITN7763001. This in turn and unsurprisingly caused further distrust of IBCA: see the Written Statement of ANON para 29 WITN7756001 and the Second Written Statement of Colin Midgeley para 6 WITN3968002 by way of example.

[282] Nick Thomas-Symonds Transcript 7 May 2025 p172 INQY1000283. This was a reference to a compensation scheme introduced after British Coal (as it then was) was found liable in 1998 for vibration white finger, and for chronic lung disease caused by coal dust. Fees were paid under a claims handling agreement by the Department of Trade and Industry (DTI) to solicitors' firms acting for the claimants. One firm, Beresfords, was said to have registered 97,500 claims. That firm (Beresfords) received not only proper fees paid by the DTI but, in addition, charged their clients illegitimate success fees (conditional or contingency fees) payable out of their compensation, without properly informing their clients that the government would pay solicitors' fees and that other firms were not charging success fees. Moreover, they paid impermissible referral fees to those who introduced miner clients to them, and in some instances paid those introducers out of the client's compensation: these were sums for which the clients received no benefit. They were struck off, and appealed to the High Court. Rejecting the appeal by the solicitors, the judges accepted that, in summary, "*Beresfords' clients were subjected to obviously inappropriate and unnecessary payments to claims management organisations, in circumstances where Beresfords were themselves acting under a conflict of interest. In the result, sums in excess of £1.5m. were deducted from their clients' compensation, none of which, we are told, has ever been repaid.*" These facts are taken from [2009] EWHC 3155 (Admin), a judgment of a three-judge Divisional Court of the Queen's Bench Division. The court referred as one example of a case to that of a miner's widow, who was advised by Beresfords to accept an offer of £281.77. Beresfords were paid costs of £2,431.08 by the DTI, and also took a success fee of £65.40 from the compensation with the result that the miner's widow received £217.73 and Beresfords were paid £2,495.48. Beresford, Smith v The Law Society [2009] EWHC 3155 (Admin) RLIT0002960

been agreements reached between IBCA and recognised legal representatives (who can be trusted not to put themselves in a position where their own financial interests conflict with their client's best interests by seeking any further payments from those clients) which provide for agreed fees at a level which enable adequate work to be done by those firms.

It is of the utmost importance that all people infected and affected should be made aware firstly (and at the very outset of their interactions with the claim manager) of their entitlement to legal support, and secondly that such support is available to them and at no charge to them whatsoever from the solicitors' firms with whom IBCA has contracted for that purpose. A simple Google search shows that there are firms of solicitors who are offering assistance with infected blood compensation claims on a "no win no fee basis". This would typically mean that the individual pays a fee to the solicitor out of their compensation. The Solicitors Regulation Authority has told the Inquiry that it is prepared to write to remind solicitors of their obligations.[283] It can be made clear on websites by campaign groups and charities that any person entitled to claim should expect that they will not be asked by any solicitors' firm for any payment. If a firm proposed to seek any payment – conditional or contingent ones included – from an applicant, they would be bound as a matter of professional ethics to ensure that their client knew that they could obtain a similar service from other solicitors without having any such payment to make.

In the result, IBCA has missed an opportunity to have worked with the recognised legal representatives, to use their experience and familiarity with the broader history and evidence as well as the circumstances of their clients in the drawing up of policies, procedures and guidance. A recognition that lawyers are part of the solution, rather than part of a problem, has been belated.

If the scheme as drafted had been simple to apply, readily understandable, and not dauntingly complex, there might have been greater force in the view that lawyers were not essential. Nonetheless, even if the scheme had had those qualities, I did not take that view. I accepted in the Second Interim Report that there should be legally qualified assessors, that the speed, efficiency and acceptability of the scheme would be facilitated by advice and advocacy, and that there should be a service staffed by a lawyer or lawyers who gave their advice confidentially to the applicant and were under an obligation of confidence to the applicant.[284]

However, the moment that the scheme was put into force as it was, with complexities which none of those giving evidence at the May hearings doubted, the need for legal assistance was obvious. Using claim managers dedicated to individuals was not sufficient. Any person

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[283] Solicitors Regulation Authority Principle 2: "*You act in a way that upholds public trust and confidence in the solicitors' profession and in legal services provided by authorised persons.*"

Soliticitors Regulation 8.6 "*You give clients information in a way they can understand. You ensure they are in a position to make informed decisions about the services they need, how their matter will be handled and the options available to them.*"

[284] Infected Blood Inquiry Second Interim Report 5 April 2023 p22, p55 INQY0000453

reading the closing submissions to the Inquiry in respect of this Additional Report will be left in no doubt that lawyers are needed in the process.

It is a matter of regret that IBCA did not think earlier of using the vast resource of goodwill and experience that recognised legal representatives represent. I discuss how to make better use of the lawyers in the chapter on *Recommendations*.

IBCA's slow start

The rate of making payments and the uncertainty whether individuals would be paid within a reasonable timescale, or indeed their lifetime, has been an almost universal concern to those likely to be eligible for compensation.

A short chronology

On 22 July 2024 IBCA produced its first newsletter. This explained that work was underway to "*create the organisation and recruit a team to design and deliver that*": "*We'll need to start small to ensure we get this right, working with you through every stage of the development, and in the meantime we absolutely commit to keeping you updated regularly on how that work is progressing.*" IBCA was, it said, committed to those impacted by the infected blood scandal being at the centre of "*our planning and delivery for the compensation scheme, including how we ensure it's designed around you*".[285]

In its 17 September 2024 newsletter, IBCA explained that it was aiming for the very first payments to be made before the end of 2024, with the expectation of scaling up the service in early 2025.[286]

IBCA's 10 October newsletter reiterated the intention to make the first compensation payments by the end of 2024 ("*starting with small numbers initially*") and trying to make sure that the process "*is as simple as possible as we build it, before we then open it up to a larger number of people.*"[287]

On 17 October 2024 David Foley explained in the newsletter that the first 20 people would now be invited to start their claim.[288] This was followed on 24 October by a further newsletter which explained that the first claim managers had joined IBCA.[289]

In its 13 November 2024 newsletter IBCA explained its intention to send out further invites to claim, in small numbers again, before the end of the year.[290]

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[285] The newsletter described two opportunities to support IBCA's work: the recruitment of a user consultant and volunteers for an advisory panel for communications, who would be willing to look at, comment on or contribute to news and updates. It was published on gov.uk on 31 July 2024. IBCA Newsletter 22 July 2024 pp4-5 RLIT0002961

[286] IBCA Newsletter 17 September 2024 p4 RLIT0002962

[287] IBCA Newsletter 10 October 2024 p3 RLIT0002469

[288] IBCA Newsletter 17 October 2024 p4 WITN7762006

[289] IBCA Newsletter 24 October 2024 p3 RLIT0002965

[290] IBCA Newsletter 13 November 2024 p5 WITN7762009

In its 2 December 2024 newsletter, IBCA explained that it would be sending out a small number of invitations to people to start their claim, with the aim of reaching around 250 claims in early 2025. In terms of whether and if so how to prioritise certain claims, on which subject IBCA had sought views, the newsletter reported that "*we have heard that age, severity and length of infection are just some of the facts we should consider, and we are seeking views on anything else we should include in these decisions for further invites.*"[291]

The 11 December newsletter reported that in the last few days compensation offers had been made and the first payments of compensation would begin. It addressed the position of those infected with Hepatitis B, explaining that IBCA would keep people updated as to when such claims would be open.[292]

The 8 January 2025 Community Update stated that the first compensation offers had been made to 10 people, and that IBCA had "*opened claims to a further group of 25 people*", with a plan to have "*brought in around 250 people to claim*" by the end of March.[293]

By mid January 2025, 67 people had been asked to start their claim.[294]

IBCA's 10 February 2025 Community Update outlined its plans for opening the claim service in stages. It stated that "*Some people from all groups will be able to claim in 2025, although not all claims from all groups will be completed by then. By developing and testing at each stage, some people from each group should have received their payments by the end of the year.*"[295]

As at 14 March 2025 IBCA reported that 63 offers of compensation had been made and 255 people had been asked to begin their compensation claim.[296]

On 14 April 2025 IBCA announced that it would prioritise claims for those nearing the end of their life.[297]

On 1 May 2025 IBCA announced that on average they would ask 100 people to start their claims each week.[298]

On 14 May 2025 David Foley confirmed in IBCA's Community Update the evidence he had given to the Inquiry: "*we expect to have brought in to claim all those who are infected and registered with a support scheme this calendar year.*"[299]

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[291] IBCA Newsletter 2 December 2024 p4 RLIT0002963

[292] IBCA Newsletter 11 December 2024 p3, p6 RLIT0002964

[293] IBCA Community Update 8 January 2025 p3 WITN7757002

[294] IBCA Community Update 10 February 2025 p3 RLIT0002482

[295] IBCA Community Update 10 February 2025 p7 RLIT0002482

[296] Second Written Statement of David Foley para 12 WITN7757010

[297] IBCA website IBCA to prioritise claims for those who are nearing the end of their life 14 April 2025 RLIT0002492

[298] IBCA Community Update 1 May 2025 p1 RLIT0002946

[299] IBCA Community Update 14 May 2025 pp3-4 RLIT0002970

As at 19 June 2025, a total of 1,707 people have been asked to start their claim, of whom 1,346 have started the process; 462 people had received an offer, and 310 had had their compensation paid.[300]

Projected timescales for paying compensation

The framework document agreed between the Cabinet Office and IBCA "*assumes that the bulk of payments to the infected are completed by no later than 2027, and the bulk of payments to the affected are completed by no later than 2029.*"[301] David Foley states: "*both IBCA and the Cabinet Office are clear that these dates are not targets and that IBCA is aiming to process claims more quickly than this.*" James Quinault concurs: "*the Cabinet Office understands "the bulk of payments" to mean that all payments to people infected and affected should have been made by the end of 2027 and 2029 respectively, apart from payments to people who have not yet come forward; or who have come forward only just before those dates, so that there has not yet been time for IBCA to process their claim or for the three months which claimants have to accept an offer to have elapsed.*"[302]

In his third statement, David Foley referred to discussions with the Principal Accounting Officer within the Cabinet Office which were ongoing, but which indicate that "*IBCA will have the resources and agreements necessary to take the appropriate steps to go faster.*" On this basis, he believes that IBCA "*should have begun claims for all those who are living registered infected this year*" and "*will seek to open claims routes for all other groups as soon as possible, continuing to use a test-and-learn approach, including beginning to process affected claims this year.*"[303]

Impact upon people infected and affected

It is overwhelmingly clear from all of the evidence, letters, emails and calls that the Inquiry has received that there is grave concern regarding the delay in compensation being delivered, the lack of any clear timescales as to when it will in fact be delivered, and the impact of this uncertainty.

> "*The impact of the delays on the community has been devastating. We're suffering from compounded trauma, anger, frustration, exhaustion, and a loss of hope. We're experiencing an even further decline in our physical and mental health; I have heard several reports of individuals who feel suicidal. We don't feel heard, and it's as if there is contempt towards us. We have been left confused by conflicting and incorrect information and moving goalposts.*"[304]

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[300] IBCA website Statistics: Compensation progress update: 19 June 2025

[301] IBCA Framework Document para 7.1 WITN7755002

[302] Third Written Statement of David Foley para 39 WITN7757011, Third Written Statement of James Quinault para 71 WITN7755006

[303] Third Written Statement of David Foley para 40 WITN7757011. See also David Foley and Sir Robert Francis Transcript 8 May 2025 p46, p49 INQY1000284

[304] Third Written Statement of Carolyn Challis para 20 WITN0622013

"*The biggest impact is the devastating delay… Victims are confused, bewildered and frightened as they wait for their compensation to begin its process, not knowing where they are or will be in the timeline. The distress of loss and bereavement becomes acute, and the torture pertains. The need for justice alienates them from Government and the IBCA and drains their confidence in a process that seems bereft of reasonableness in time and understanding of circumstances. The ongoing long-term sense of victimhood can become stifling. I assume a weight which only depresses and overpowers with resentment, emotional and psychological distress.*"[305]

"*We are in complete despair over* [the projected timetable for paying out claims], *as many of us will not live long enough to see our final award paid out, let alone being well enough to use the money as we would have wished.*"[306]

"*My mum has cancer and is on borrowed time. The government knows that the longer they wait to pay out the compensation, the more people will die and the less money they will have to pay. My mum needs and deserves her compensation now, not in 2029. The doctors have told her she has between one and three years, potentially five if she is extremely lucky. People don't have the luxury of time to wait any longer for their compensation. My mum needs to be in a nursing home. She can't cook for herself; she struggles to walk and is in constant pain. When my mum first got her cancer diagnosis, she went into the nursing home. She is back home now because we cannot afford their fees. My mum has spent her life looking after the family, her sons and my dad. Now mum needs help, there is none.*"[307]

"*The single biggest source of anxiety amongst the infected and affected community is the length of time which it is taking to begin to process claims of any number. A number of clients contacting us are clearly traumatised by this. The common assumption is that it is a deliberate tactic so that numbers of victims will tragically die before their claims come to be considered.*"[308]

"*CBC members have been consistently asking for a timescale setting out when they can expect to receive their compensation so that they can manage their financial affairs.*"[309]

"*Clients are extremely worried and anxious about the timescales for making their claim and the delay that they might face in being able to make their claim and in their claim being finalised. It is still unclear exactly when the scheme will open to different categories of claim.*"[310]

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[305] Second Written Statement of Nigel Hamilton paras 63-64 WITN2340014

[306] Letter from Sue Threakall to Sir Brian Langstaff 20 April 2025 p3 SUST0000001

[307] Second Written Statement of Colin Midgeley para 5 WITN3968002

[308] Written Statement of Michael Imperato para 64 WITN7761001

[309] Second Written Statement of Glenn Wilkinson para 23 WITN2050115

[310] Written Statement of Patrick McGuire para 43 WITN7760001

> "*Another big concern is that affected people seem to be "at the back of the queue". I find this very worrying. Affected people's claims will die with them. Therefore, there may be many quite elderly and ill "affected persons" that will never see any compensation because they will die before their cases are considered … Also it seems very odd that they don't take families as a unit. Affected victims will normally be associated with an infected victim. Surely it will be easier to deal with them together at roughly the same time?*"[311]
>
> "*… the glacial pace of IBCA to start even registering the affected led many affected widows (and parents) to fear they will never see their compensation.*"[312]
>
> "*Some people are scared that they won't be compensated in time to utilise their awards to ensure that they are able to enjoy what is left of their lives. Some people are scared that they won't be compensated in time to put their affairs in order and ensure that there is provision for their families once they are gone. Some people are scared that they will need to fight for another decade or more just to get what Sir Brian said they should get … All any of us want now, is to be paid our compensation and to be left alone to get on with the rest of our lives.*"[313]

It is plain from the evidence which the Inquiry has received that the uncertainty as to when an individual may be asked to begin the compensation process is itself causing a significant degree of distress and anxiety. Sean Cavens, a campaigner, describes "*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.*"[314] Clair Walton, who was one of the founders of Positive Women and is a user consultant for IBCA, explains that "*I have no idea when I will be able to make my claim for compensation and I have no idea when the scheme will open up to applications without invitation. This is the biggest source of anger and upset for everyone waiting to make their claim. More information needs to be given about anticipated timescales because as matters stand, we don't know whether it will be two months or two years before we are able to make our claims.*"[315] Gary Webster, a former Treloar's pupil, states that "*We cannot make any plans, we are in limbo and don't know if and when we will get compensation so how do you plan, you cannot … It is constantly on my mind, I worry what next are we going to get the magic email or will it be the end of the year, we just don't know. Why are they treating us like this?*"[316] An anonymous witness told the Inquiry: "*One thing they could do is set out a proper timetable about which people are getting paid and when, we all want it dealt with so we can move on with life.*"[317]

Those who gave oral evidence to the Inquiry on 7 May 2025 believed that more could be done to speed up the process of paying compensation. Nigel Hamilton, chairman of

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[311] Second Written Statement of Danielle Mullan para 26 WITN2439002

[312] Written Statement of ANON para 18 WITN7756001

[313] Written Statement of ANON and Alan Burgess para 53 and para 55 WITN7752001

[314] Fourth Written Statement of Sean Cavens para 15 WITN1146047

[315] Fourth Written Statement of Clair Walton para 15c WITN1589029

[316] Second Written Statement of Gary Webster para 26 WITN1723044

[317] Written Statement of ANON para 17 WITN7758001

Haemophilia Northern Ireland, considered that change to the existing process could achieve improvement, including "*Surely, it would have been far quicker for people to send in their applications with key information/documents … If that process had been adopted, hundreds of us would now have had our cases 'in the system'*" and "*More case officers or claims managers, or whatever the mantra is, into the cases so we get a reasonable timeline that people can accommodate and come to terms with which will give us a degree of justice.*"[318] Caz Challis, who campaigns on behalf of people who were infected but not eligible for the support schemes and so have yet to receive any financial support or compensation, suggested a simplification of some elements of the scheme: "*The whole scheme should be simplified in order to speed up the roll-out of compensation … People cannot be expected to be constantly retraumatised searching for evidence that is unlikely to exist just to prove how very ill they are.*"[319] Nick Thomas-Symonds accepted, having regard to the number of people who had been paid by that stage, that this was "*absolutely*" a "*profoundly unsatisfactory state of affairs*".[320] He told the Inquiry that he saw his role as "*questioning, pushing, asking, pressing forward on the speed of payments*".[321] This included discussions about "*appetite for risk, taking more risks*" and "*what is it in terms of procurement, for example, that we can do to speed this up, what can we do in terms of additional people, additional case workers, what are the steps?*" He confirmed a commitment from the Government to provide IBCA "*with all reasonable resources necessary to make payments as soon as possible.*"[322]

The Inquiry began the hearings in May with the object of being constructive and identifying what actions can be taken by the Government and Infected Blood Compensation Authority to address the concerns. That inevitably leads to setting out what is understood about the way in which IBCA currently progresses compensation, before proposals can sensibly be made to speed up the process.

The system for deciding who to ask to claim

The only applications for compensation which IBCA is presently determining are those from people infected and registered with one of the four national support schemes. Beyond prioritisation for people who have been told they are nearing the end of their life, the process is one of random selection: "*So we have a list of those who are registered with the existing Infected Support Schemes. They are put into a spreadsheet and then a random allocation is generated which produces the individual cases that we then use to proceed to start the claim.*"[323]

Whether, and if so to what extent, this system should be modified is considered in the chapter on *Recommendations*.

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[318] Nigel Hamilton Transcript 7 May 2025 p37, pp89-90 INQY1000283

[319] Caz Challis Transcript 7 May 2025 p80 INQY1000283

[320] Nick Thomas-Symonds 7 May 2025 p136 INQY1000283

[321] Nick Thomas-Symonds 7 May 2025 p125 INQY1000283

[322] Nick Thomas-Symonds 7 May 2025 pp139-140 INQY1000283

[323] David Foley Transcript 8 May 2025 p63 INQY1000284

The way compensation is processed

David Foley described in evidence how a claim was progressed. "*It obviously starts with starting the claim and, at that point, the claims manager will write to the individual.*"[324]

The initial claim is currently made by a person already registered with a support scheme. It is not initiated by a written application from that person but as the result of a decision being made that a given person on the appropriate register is to be asked to make a claim. Once that decision has been made, the claim manager then obtains information from the support schemes about the individual. They then contact the individual to ask if they will make a claim. It is thus not the case that the process "starts with the claim" – some work will already have been done, gathering information from various sources, becoming familiar with it and only then speaking to/contacting the individual.

> "*The first stage, then, is preparing the right information in order to calculate the claim. Now, we – our ethos is that we are supporting people to get the right compensation. And the first thing that we do, and we do this prior to starting them, is gather the right sets of information for them and say: with the information that we already hold, this is the information that we think is -- do you think this is the right information? Is there anything you would like to change? Is there anything that you would like to add? Do you have anything -- indeed, you may have a representative who has something as well. Is there anything that you would like to provide?*"[325]

That leads on to what is called the "declaration letter":

> "*having presented all information we have, having the chance for the individual to give all the information they have. It's also at that point that the individual says: I think there's a bit of other information somewhere that I don't have, and we'll say: we will go and get that for you if you would like us to. Once we've got to that point, we then write in the declaration letter and say: this is the information that we have and upon which we will calculate the claim. That letter is issued by the claims manager. The individual whose claim it is then writes back and says: I am happy that this is the information upon which you calculate the claim. Once we receive that reply, we then make the calculation.*"[326]

By way of comment, many people will already have given significant details to the scheme with which they are registered, and a very significant proportion of them will have prepared evidence for the Inquiry which would have involved them giving many of those details to a third party once again. They will often have obtained medical records and reports after they had been registered with the scheme, for instance for the Inquiry and any litigation, and these would not necessarily be held by the scheme. The claim manager, however knowledgeable

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[324] David Foley Transcript 8 May 2025 p26-30 INQY1000284

[325] David Foley Transcript 8 May 2025 p27 INQY1000284

[326] David Foley Transcript 8 May 2025 p29 INQY1000284

and well-intentioned, is highly unlikely to have developed the closeness of relationship with the individual, and the familiarity with their case, which their legal representatives will have done. It is likely to be significantly speedier first to ask the individual if they or their representatives have the relevant documents or evidence, or if they know what evidence may or may not be available, and take matters from there. In such a case the preparation described by David Foley in his example of a claim would not usually be needed.

> "*The calculation is done by the claims manager, and then we write back with an offer, and the individual then has the chance to consider the offer and to decide if they think it is the appropriate offer. If it is, then they can write back and say: I accept the offer. And then we will put the claim into payment, and it is paid four days later from that.*"[327]

There was a further and necessary step, which is that

> "*in order to make the payment, we need the agreement of the claims manager, a financial assessor who checks the calculations and the Authority's -- a fraud assessor who checks that this is not a fraudulent account, and then a supervisor. And it's the four -- it requires agreement from all four in order to press the button and make payment.*"[328]

David Foley accepted that in many cases experience had shown the documentation held by support schemes to be either quite limited or rather variable.[329] He added that for those registered with support schemes there might be a question as to evidencing the point of infection. He accepted too that there had been cases where many people had not been diagnosed for years, or diagnosed by their clinicians but not told for years, or in which there were no records recording an accurate date of diagnosis until something came up much later which was not the actual date of diagnosis but a first proper record of it in medical records.[330]

Obtaining information from clinicians

The Inquiry has received submissions from the UK Haemophilia Doctors' Organisation ("UKHCDO") which record that "*UKHCDO have significant concerns about the questions asked by IBCA*" of haemophilia centres.[331] UKHCDO explains that questions received by IBCA can be very time consuming to answer and that in many instances the data requested

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[327] David Foley Transcript 8 May 2025 p29-30 INQY1000284

[328] David Foley Transcript 8 May 2025 p30 INQY1000284

[329] David Foley Transcript 8 May 2025 p32 INQY1000284

[330] David Foley Transcript 8 May 2025 pp33-34 INQY1000284

[331] Written Submissions on behalf of UKHCDO para 8 SUBS0000083

is not available or is unknowable.[332] It is not difficult to see how this might contribute to the delay in determining compensation claims.[333]

The Inquiry understands from UKHCDO (and has no reason to doubt) that:

- questions are being asked which are based on modern diagnostic standards and technologies which were unavailable at the time of the infections.[334]
- questions are being asked that are ambiguous, unanswerable because the information is not available or the answers would be misleading (for example the date of Hepatitis C infection will be unknown for many people) or which seek information that is not necessary to assess the compensation claim or which could be more efficiently obtained elsewhere.[335]
- there is a need for greater clarity in the questions asked, and the reasons for asking them, so as to ensure that the clinician is correctly interpreting the question as intended by IBCA.[336]
- haemophilia centres are unnecessarily being asked for the date of diagnosis of Hepatitis C (which, as set out elsewhere in this Additional Report, is not in fact relevant to the assessment of compensation), causing delay and adding to clinicians' workload.[337]
- haemophilia centres are being asked about the date of the actual blood treatment which resulted in the infection which in most cases is not known or knowable.[338]
- requests are being made for data which the national support schemes already have, including in some cases confirmation of the diagnosis of HIV or Hepatitis C even though the individual's eligibility has already been accepted by the support scheme.[339]
- irrelevant questions are being asked e.g. about the person's haemophilia, or about their current health when they are no longer under the care of the centre.[340]

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[332] Some questions may take "*up to four to six hours per claimant, sometimes even longer, as before confirming that the information is missing or not available, clinicians must go through the entire record page by page. The information must often be searched for in archived, often microfilmed records, making them very laborious to go through, with no guarantee of finding the information requested.*" Written Submissions on behalf of UKHCDO para 9 SUBS0000083

[333] UKHCDO note that the time required for clinicians to respond to these requests can be significant and that this is likely to cause delays to people with bleeding disorders awaiting compensation. Written Submissions on behalf of UKHCDO para 11 SUBS0000083

[334] Written Submissions on behalf of UKHCDO para 10 SUBS0000083

[335] Written Submissions on behalf of UKHCDO paras 17-18 SUBS0000083

[336] Written Submissions on behalf of UKHCDO para 18 SUBS0000083. UKHCDO notes the risk of a claimant being undercompensated if a clinician has not used the same interpretation of a question as intended by IBCA, which underlines the importance of clarity about what information is being sought and why.

[337] Written Submissions on behalf of UKHCDO para 18.4 SUBS0000083

[338] Written Submissions on behalf of UKHCDO para 18.8 SUBS0000083

[339] Written Submissions on behalf of UKHCDO para 19 SUBS0000083

[340] Written Submissions on behalf of UKHCDO para 19.2 SUBS0000083

UKHCDO suggests that it is unclear whether IBCA has had clinical input into the questions that claim managers are asking or what discussion there has been of the need or value for each question so that they can be kept to a minimum (and thus reduce delay), and observes further that questions are received in a variety of formats,[341] and that there is no established line of communication or dialogue between IBCA and haemophilia centres.[342]

In light of the fact that until very recently IBCA had only one clinical assessor, and had not yet established its Clinical Panel, it may very well be the case that the difficulties described by UKHCDO are, at least in part, attributable to the lack of clinical input into the requests being made to haemophilia centres. A further contributing factor may well be the lack of involvement of people infected and affected and their legal representatives, as described earlier in this chapter.

The reasons for IBCA's slow start

That there has been a slow start is obvious. The numbers who have received compensation to date are, as the Minister accepted, profoundly unsatisfactory. I say this not as a matter of criticism, but as an observation. It is also right to record that the numbers have increased significantly in recent weeks, and that the intended timetable for compensating living people infected who are registered with a support scheme has moved forward significantly with the announcement at the Inquiry hearings in May.[343] IBCA says it now expects to have begun all their claims by the end of this calendar year.

It is likely that there may have been a number of factors contributing to this state of affairs. The complexity of the scheme as introduced, and the lack of involvement of people infected and affected in its design and operation, has undoubtedly had a role to play. IBCA's decision to "start small" and adopt a test and learn approach is a factor. The process described above of the claim manager gathering information which the individual or their lawyer may already hold (or seeking information which the individual or their lawyer may know does not exist) will have had a bearing on speed. The reluctance to involve lawyers and the reluctance to encourage individuals to submit fully-prepared applications without waiting to be asked is a further factor. So too is the way in which information has been sought from haemophilia clinicians (as described above by UKHCDO). The appetite for risk, as described by the Minister, may have contributed to a cautious start. The numbers of claim managers and clinical assessors may also have been a limiting factor. So, too, is the effect of IBCA's view that it is solely responsible for collecting relevant evidence and preparing a person's claim: it may be creating work which it is unnecessary for a claim manager to do. Though there are cases where IBCA needs to exercise its powers to compel documents and information,

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[341] Written Submissions on behalf of UKHCDO para 29 SUBS0000083

[342] UKHCDO states that "*when criteria and questions change, Centres are not informed, cannot prepare and cannot let IBCA know in advance when there are likely to be problems with the criteria or questions.*" They propose the establishment of "*regular communication between IBCA and haemophilia centres*", which UKHCDO says it would be happy to facilitate. Written Submissions on behalf of UKHCDO para 13 SUBS0000083

[343] See also David Foley Transcript 8 May 2025 p46 INQY1000284. Confirmed in the IBCA Community Update 14 May 2025 pp3-4 RLIT0002970

there are probably many cases where the evidence exists and is already in the possession of the individual or their legal representative. If accessed at an early stage, the availability of this documentation should enable faster progress towards the declaration stage and offer.

What matters most now, however, is to identify what actions can be taken (beyond those which have already been taken in recent weeks) to speed up the process. The Inquiry's suggestions in this regard are addressed in the chapter on *Recommendations*.

Internal review

I turn finally in this chapter to the question of review and appeal. The length of time that people have been waiting for compensation (and thus for justice) reinforces the importance of ensuring that decisions on compensation in individual cases are correct. Although simplicity was an objective in designing the scheme, in practice the complexity of the Regulations means that there will inevitably be cases where justice requires a review of, and appeal against, the decision.

Regulation 82 of the 2025 Regulations provides for IBCA to undertake internal reviews of determinations at the request of an applicant.[344] The request must be in writing and signed, must specify the grounds on which the request for a review is made, and be given to IBCA within a period of three months of notice of the original determination.[345] The applicant may submit further evidence.[346] On review, IBCA can confirm the original determination, or revoke it and make a new determination.[347] It must take reasonable steps to ensure that the review is carried out by a member of IBCA's staff who had no involvement in the making of the original determination.[348] An applicant who is dissatisfied with the decision made on a review may appeal to the First-tier Tribunal.[349]

David Foley told the Inquiry that the review "*is done internally, and it's done by a different person than assessed the original thing*" and that it is a paper-based exercise rather than one in which the individual can attend and make oral representations to the person undertaking the review.[350] He agreed that the details of the process could be published on IBCA's website. As at the date of writing this Report there is limited detail there regarding the process. However, in the written statements provided to the Inquiry following the hearing

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[344] Regulation 82(1) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp83-84 RLIT0002944

[345] Regulation 82(4) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p84 RLIT0002944

[346] Regulation 82(5) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p84 RLIT0002944

[347] Regulation 82(8) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p84 RLIT0002944

[348] Regulation 82(7) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p84 RLIT0002944

[349] Regulation 84 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p86 RLIT0002944, Section 52 of the Victims and Prisoners Act 2024 p51 RLIT0002954

[350] David Foley Transcript 8 May 2025 pp73-75 INQY1000284. It is right to note that as at the date of the hearing on 8 May 2025 there had been no requests for reviews under regulation 82.

in May, David Foley describes a proposed process of "Appeal Panels". This is an "appeal" internal to IBCA and is "*part of the process by which IBCA can support a request for a review of a case*". The process is as follows:

> "*If a person making the claim or their representatives wants a review of their decision, they can request this, as per the Regulations, for three reasons: eligibility; the amount of compensation offered; or the recipient of the compensation.*
>
> *Once the request for review is received IBCA will assign a new claims manager and also 'stand up' the panel to consider the request. The panel will be made up of the claim manager, a financial assessor, in-house legal support, clinical advisors (if required by the nature of the request), and quality assurance.*
>
> *The new claims manager will reach out to the person making the claim to discuss the review including any evidence which the person making the claim wants to raise.*
>
> *After consideration by the panel the person making the claim will be informed in writing of the outcome of the review and will also be offered a call with the claim manager to discuss the outcome. If the review has resulted in a revision of the offer then a new offer letter will be issued.*
>
> *If the person making the claim still feels that they have not received the correct compensation offer then they can appeal to the First-tier tribunal for an independent review.*"[351]

Four points arise in relation to the question of review and appeal.

First, I note that there is still no provision (even under IBCA's new appeal panel process) for any oral representations to be made, or for the individual or their lawyer to attend the appeal panel.

Second, I note and welcome that legal support is available to the individual for the purposes of the review. There is, however, no funded legal support for an individual who wishes to appeal to the First-tier tribunal.

Third, it is fundamental to the fair operation of the review process that written reasons for the original determination are provided. As the submissions made on behalf of the core participants represented by Thompsons Solicitors (Scotland) note, people are entitled to know how, by whom and why decisions in individual cases have been reached.[352] It may be that in practice claim managers are explaining the basis for their decisions[353] but whether this is done or not should not be left to the individual judgment of claim managers.

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[351] Fifth Written Statement of David Foley para 10 WITN7757022

[352] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.74(c) SUBS0000084. See also the Written Submissions on behalf of the core participants represented by Watkins & Gunn para 14 SUBS0000091

[353] The Inquiry has seen some examples of email communications from claim managers in individual cases which do explain the reasons for a particular decision.

Rather it should be an express requirement in published guidance, so that people know what to expect.

Fourth, it is important that there is a defined mechanism whereby people who have been the subject of either a mistake or a change in the Regulations, or in IBCA's policies, or in their interpretation of a Regulation, can be informed of this and an internal review facilitated.[354]

Commentary

This chapter has examined the way in which IBCA has been set up and the nature and extent of its functions and powers. I have found that it is an Arm's Length Body in the sense that it has the statutory powers and operational ability to make decisions on claims, determine eligibility, assess individual entitlement to compensation and make payments in accordance with the Regulations. However, its powers are circumscribed by the fact the compensation scheme was designed and structured by the Government, the rules on eligibility were determined by the Government, and the tariffs and bands of compensation were devised and set by the Government. IBCA's role when it considers individual claims is, in effect, to apply the rules devised by Government and set out in the Regulations.

Because IBCA has been set up in this way, with more limited powers and functions than envisaged in the Inquiry's Second Interim Report, it is all the more vital that IBCA and the Cabinet Office act transparently, so as to promote IBCA's "*operational independence*", and so as to ensure the involvement of people infected and affected to as great an extent as possible. This has not thus far been achieved. There is no material to show that IBCA has consulted with, or taken advice from, any person or body other than the Cabinet Office on the meaning of the Regulations,[355] though it intends to establish a Clinical Panel to provide independent expert advice on the interpretation of the Regulations. It has not yet established an advisory board[356] or other means of ensuring a formal, significant and influential role for people infected or affected within IBCA. There has been little meaningful consultation with people infected and affected or their legal representatives about IBCA's policies and processes.

IBCA is not yet living up to its commitment to be transparent, though there are indications of some willingness to improve on this.[357] The significant role played by clinical assessors in IBCA's decision-making has only recently become apparent as a result of the Inquiry's further hearings. The guidance, advice and instructions to claim managers have not been published. The work undertaken by IBCA with the Cabinet Office to understand the policy

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[354] As the Written Submissions on behalf of the core participants represented by Milners Solicitors suggest at paras 164-167 SUBS0000086

[355] The meaning of Regulations is ultimately a matter for the court to determine. However, the process of court determination can take time, and it is thus wise to check if there are other interpretations, or any real doubt about what the Regulations mean. Discussion helps identify this.

[356] Though encouragingly it is now planning to do so.

[357] As, for example, in the stated intent to create an advisory board, with which of necessity more information would have to be shared: without transparency by sharing such information the advisory board would be emasculated.

intentions behind each regulation has not been shared. None of IBCA's policy papers have been published, nor has information regarding its approach to important issues within the Regulations, nor the minutes of the meetings of IBCA's Board. IBCA also missed an opportunity to have worked more closely with the recognised legal representatives of people infected and affected, in the drawing up of policies, procedures and guidance.

An almost universal concern voiced to the Inquiry is the slowness of the start made by IBCA in making and the likely delay before compensation is received. The lack of clear timescales and the uncertainty as to when any individual might expect to receive compensation has been a source of considerable distress and anger. Although it is fair to note that the numbers who have received compensation to date have increased significantly in recent weeks, they were profoundly unsatisfactory at the start of May when the Inquiry hearings began. A number of factors probably contributed to this position. They include the complexity of the scheme, the lack of involvement of people infected and affected in its design and operation, the approach IBCA has taken to the gathering of information, an apparent reluctance to involve lawyers or to encourage individuals to submit fully-prepared applications, the way in which information has been sought from haemophilia clinicians, the initially small (though growing) numbers of claim managers and clinical assessors, and IBCA's approach to risk.

Though changes have already been made to the intended timescales within which compensation will be paid, and although it is clear to me that Nick Thomas-Symonds for his part places a heavy emphasis on speed of delivery, which both Sir Robert Francis and David Foley have echoed in their evidence, this chapter shows that there is room for further improvement in the processes by which compensation is delivered. In line with its aim of being constructive and identifying what actions can be taken by the Government and Infected Blood Compensation Authority to address the concerns, a number of recommendations follow in the chapter on *Recommendations* (see in particular Chapters 9.2 and 9.3).

4 HIV transmitted before 1982

On 22 April 2025 an IBCA claim manager[358] wrote an email to an applicant and his solicitor, stating:

> "*The HIV liability window under the Infected Blood Compensation Scheme begins on 1 January 1982, even though there is evidence that some individuals may have contracted HIV from blood or blood products prior to this date.*
>
> *This cut-off is not a reflection of whether infections happened before 1982 – we fully acknowledge that they did. Rather, it reflects the point at which, based on current legal advice, it is considered that the UK Government and health authorities should reasonably have foreseen the risk of HIV transmission through blood and blood products and taken precautionary action.*
>
> *Legal Basis for 1982 Start Date*
>
> - *The year 1981 saw the first published cases in the United States of what was later understood to be AIDS, but at the time, the cause was unknown.*
> - *By early 1982, there was emerging international evidence linking a new transmissible virus to blood and blood product use – particularly in haemophiliacs in the United States.*
> - *This included reports suggesting that a blood-borne agent was likely responsible, raising red flags about the safety of the blood supply and commercial clotting factor products.*
> - *From this point onward, the Government is considered to have had a duty to investigate and act, given the growing scientific concern and international awareness.*
>
> *The legal test for liability focuses on what the Government knew or ought to have known, and whether it failed to act on that knowledge in a way that could have prevented harm. Therefore, infections that occurred before 1 January 1982 fall outside the liability window because – based on current legal advice – it is not accepted that the risk was reasonably foreseeable by UK authorities prior to that date, nor that they were under a legal duty to act differently at that point.*
>
> *We recognise that for those infected before 1982 – and for their families – this distinction can feel deeply unfair. Their suffering is no less significant, and many understandably feel that they were failed by the system. We also acknowledge that campaigners are continuing to challenge these legal boundaries, and such challenges may shape future decisions or legislative changes. However,*

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[358] Email from IBCA to Collins Solicitors and a Collins client on 22 April 2025 DHOL0000003. Nothing in this Additional Report is intended as any criticism of the claim manager, who was no doubt doing their best to convey a position that was not of their making.

> *at present, the Scheme is required to operate within the legal framework set by the Infected Blood Compensation Scheme Regulations 2024,*[359] *and those regulations currently do not allow discretion or flexibility to extend liability outside the dates set out.*"

The reference to the "*legal framework*" set by the Regulations is presumably a reference to what is now Regulation 3 of the 2025 Regulations which contains the definition of an "eligible infected person" for the purposes of the Regulations.[360] Under Regulation 3(2)[361] this is a person who:

(a) has received, in the course of NHS treatment or armed forces treatment overseas, infected blood treatment,

(b) was subsequently diagnosed with an infection specified in paragraph (3),[362] and

(c) began, or continued, receiving the infected blood treatment during the period specified in paragraph (4).

The period specified in paragraph (4) is:

(a) for a person diagnosed with HIV, 1st January 1982 to 1st November 1985;

(b) for a person diagnosed with Hepatitis C, 1st January 1952 to 1st September 1991;

(c) for a person diagnosed with Hepatitis B, 1st January 1952 to 1st December 1972.[363]

A person may alternatively fall within the definition of an eligible infected person under Regulation 3(6), which applies to a person who:

(a) has received, in the course of NHS treatment or armed forces treatment overseas, infected blood treatment,

(b) was subsequently diagnosed with an infection specified in paragraph (3),[364] and

(c) began, or continued, receiving the infected blood treatment **after** the period specified in paragraph (4),[365] and

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[359] Although the email referred to the 2024 Regulations, this Report discusses the (identical) position under the 2025 Regulations.

[360] Regulation 3 also includes within the definition people who were infected as a result of transmission from an eligible infected person (see paragraphs (7) and (8)). It was Regulation 7 in the 2024 Regulations.

[361] Regulation 3(2) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p7 RLIT0002944

[362] The infections specified in Regulation 3(3) are HIV, Hepatitis C, and Hepatitis B (in the case of Hepatitis B, where the infection caused the person's death within a period of 12 months, or continued for a period of at least six months).

[363] Regulation 3(4) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p7 RLIT0002944

[364] The infections specified in Regulation 3(3) are HIV, Hepatitis C, and Hepatitis B (in the case of Hepatitis B, where the infection caused the person's death within a period of 12 months, or continued for a period of at least six months).

[365] Emphasis added.

(d) satisfies the IBCA that the infected blood treatment caused the person to become infected with that infection.[366]

Regulation 3(6) is thus concerned with the eligibility of those who were infected **after** the periods specified in paragraph (4), ie after 1 November 1985 in the case of HIV, after 1 September 1991 in the case of Hepatitis C, and after 1 December 1972 in the case of Hepatitis B.

There is no equivalent position for a person infected **before** the periods specified in paragraph (4). In the case of a person infected with Hepatitis C or B, that is unlikely to give rise to any injustice, given that the relevant date is 1 January 1952. But real injustice is caused in the case of a person infected with HIV before 1 January 1982.

Evidence received subsequent to the hearing on 7-8 May

Following the hearing on 7 and 8 May 2025 the Inquiry received further evidence relevant to this issue. This included the disclosure of relevant documents by IBCA and further evidence from David Foley and James Quinault.

IBCA's Policy Forum discussed the position on 21 March 2025 and 22 April 2025. On 21 March, in the course of discussion about a "Dating principles paper", it was agreed that Audree Fletcher[367] would

> "*produce a paper on HIV infection dating to go to ExCo.*[368] *This would be based on the contents of the dating principles paper, but informed by further advice to come from COLA by 28th March 2025. AF to commission that advice from COLA.*"[369]

COLA refers to the Cabinet Office Legal Advisers.

On 22 April, the Policy Forum considered "*the HIV dating paper that had been pulled together after legal advisors had given their opinion on IBCA's current approach.*" Audree Fletcher explained that:

> "*the policy intent was that the blood disorder infection dating provision should **not***[370] *be used to undermine the liability window and confer eligibility – because that could mean payments for people decades before HIV existed anywhere in the world. The recommendation is for IBCA to:*

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[366] Regulation 3(6) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp7-8 RLIT0002944

[367] A member of the IBCA Policy Forum.

[368] ExCo refers to IBCA's Executive Committee, which is comprised of IBCA's senior leadership team.

[369] IBCA Policy Forum Minutes 21 March 2025 Item 2 WITN7757014

[370] Emphasis in original.

> 1. *Continue to determine eligibility before infection date. We will only use a pre-1982 infection date where we know someone is eligible and there is evidence of treatment with HIV-infected blood before that date.*
> 2. *Not automatically assume the start of blood disorder treatment is the infection date for HIV claims where the treatment began before 1982. We will seek evidence.*
> 3. *Capture coinfection date as a separate field on the declaration form, to recognise that we will take the earlier of the two infection dates into our award calculations. Recording infection dates for HIV and Hepatitis and a separate coinfection date allows us to avoid the suggestion that we are using an HIV infection date years before HIV, or the Government's liability for HIV, existed.*
> 4. [Celine McLoughlin, Interim Director of Digital and Service] *asked what would happen if the CO changes the start of HIV eligibility. Audree explained that if in the future the legislation is changed to reflect an earlier HIV date, we would issue top-ups to those who will as a result have been underpaid. That is separate to the question above (and would at least be clearly linked to HIV incidence).*
>
> *The group agreed to continue with its current approach and with the recommendations above.*"[371]

The HIV dating paper referred to in the above minutes was disclosed to the Inquiry on 29 May 2025. Under the heading "*Eligibility*", the paper says this:

> *"The regulations make no provision for people diagnosed only with HIV who began treatment* ***before*** *1st January 1982 but did not continue receiving infected blood treatment during or after the liability window. These people are ineligible.*
>
> *The regulations allow IBCA to* ***assume the eligibility of people registered on the IBSS during their lifetime****, on the basis of the reg14(3) stating that IBSS-registered infected people do not need to provide evidence of the cause or origin of their infection, or their diagnosis."*[372]

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[371] IBCA Policy Forum Minutes 22 April 2025 Item 3 WITN7757015

[372] Emphasis in original. This document is headed "*Draft for discussion – not IBCA policy*". IBCA paper on HIV eligibility, infection and diagnosis dating in the absence of evidence 22 April 2025 p1 IBCA0000006. IBCA has also disclosed a guidance document entitled "*Key determinations*" which states "*For direct infections, their infection years should be inside the liability window for their infection - this is the high risk period for that infection and we consider it likely that someone treated with blood products in that period was infected. If the infection year is* ***outside*** *the liability window for their infection, then they must take it to policy and clinical advisor for a decision. If it is* ***before*** *or* ***after*** *the liability window, we need to take a balance of probabilities decision with the clinical advisor because the infection might not be eligible. Claims managers should not be making these decisions without expert input.*" Emphasis in original. IBCA Key determinations May 2025 p3 IBCA0000002

David Foley, in a statement dated 20 May 2025, referring to the email of 22 April 2025, said this:

> "*The specific scenario involved a claimant without a single, known infection event. In such cases – where the infection date cannot be directly attributed to a single treatment – we apply the earliest possible date that falls within the liability window, in line with the Scheme Regulations.*"[373]

The Inquiry understands this to mean that, for example, in the case of a person who was probably infected with HIV in (say) January 1981, but who continued to be treated with blood or blood products during the period 1 January 1982 - 1 November 1985, IBCA will treat them as having been infected during that period. In such a case, the "*liability window*" does not operate to exclude the person from eligibility, but may operate to reduce the amount of compensation that they would otherwise receive.

However, the "*liability window*" does operate to exclude from eligibility a person who was infected prior to 1 January 1982 and who did not receive any further blood treatments within the liability window period. In his statement of 23 May 2025 David Foley explained that:

> "*The regulations state that, as regards HIV, someone is eligible if they began or continued to receive infected blood treatments between 1 January 1982 and 1 November 1985. IBCA is given no discretion within the Regulations to change these dates. If the person making the claim believes their infection year was prior to 1 January 1982 and they did not receive any further blood treatments within the liability window then it follows that IBCA cannot assess that person to be eligible.*
>
> *At present IBCA is only opening claims from those already registered on an Infected Blood Support Scheme who are already accepted to be eligible. Where someone is already registered on a scheme as infected with HIV but there is a lack of evidence for the infection date then IBCA uses the earliest date – within the liability window – when the infection could have been contracted.*
>
> *I have been asked whether IBCA is seeking to clarify the position or request an amendment to the Regulations. The position of the Regulations on eligibility is clear although IBCA has worked to develop policies on how to assess that eligibility.*
>
> *With regards to an amendment, as I set out in my first witness statement, "the Cabinet Office is responsible for setting the policy framework of [the] legislation which IBCA is then responsible for administering with full operational independence and accountability". IBCA provides input to the Cabinet Office "on the practicalities of delivering regulations". This is not a matter of practicality, it is a matter of the intent and scope of the Regulations and it is not IBCA's role to take a position on that.*"[374]

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[373] Third Written Statement of David Foley para 33 WITN7757011

[374] Fourth Written Statement of David Foley paras 2-5 WITN7757021

Commentary

The Inquiry has not been provided with any explanation as to how the Regulations (initially the 2024 Regulations and now the 2025 Regulations) came to be drafted in a way so as (effectively) to exclude HIV transmitted by blood or blood products or tissue before 1 January 1982. The initial information about the scheme that was published on 21 May 2024 made no reference to it.[375] Nor did the "Engagement Explainer" produced by the Cabinet Office in June 2024, which was intended to "*provide further background information on how the Scheme was designed and how the Government proposes compensation awards be calculated.*"[376] It was not addressed in the report of the Expert Group published on 16 August 2024,[377] or in the Government update published on 16 August 2024.[378] It is not even explained in the Infected Blood Compensation Scheme Summary published by the Government on 23 August 2024, which says this:

> "*The Scheme will not have hard cut-off dates for determining whether a person is eligible for compensation based on when their infection was acquired. However, the evidence requirements will be higher where a person was infected after the introduction of screening of blood, blood products and tissue … The dates the Scheme will acknowledge for the introduction of screening are:*
>
> - *HIV infection – November 1985*
> - *Hepatitis C infection – September 1991*
> - *Hepatitis B infection – December 1972.*"[379]

The Inquiry has been told that the email of 22 April 2025 was "*drafted by a member of IBCA's Operations Team and discussed with IBCA's Operational Policy Team before it was sent. The Cabinet Office was not consulted on the email before it was sent.*"[380]

Sir Robert Francis told the Inquiry on 8 May 2025 that he had not seen the email previously, but thought it "*an attempt by the claims manager or through the claims manager to explain the reason for a Government policy.*"[381] James Quinault had also not seen the email previously, and suggested that "*it would not be reflective of the Government's position on that.*"[382] In his subsequent statement of 21 May 2025 James Quinault said he did not believe that the content of the email was provided by the Cabinet Office policy team and believed it was

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[375] Infected Blood Compensation Scheme Proposal Summary 21 May 2024 RLIT0002493. Nor did the Infected Blood Inquiry Response Expert Group Interim Report 21 May 2024 RLIT0002478

[376] Infected Blood Compensation Scheme Engagement Explainer May 2024 p1 WITN7752004. Unsurprisingly, therefore, it was not an issue covered in the report of Sir Robert Francis KC following the June 2024 engagement exercise. Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p9 RLIT0002466

[377] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 RLIT0002474. Nor was it addressed in the Expert Group's initial or addendum reports.

[378] Government Update on the Infected Blood Compensation Scheme 16 August 2024 WITN7760006

[379] Infected Blood Compensation Scheme Summary 23 August 2024 pp9-10 RLIT0002945

[380] Third Written Statement of David Foley para 34 WITN7757011

[381] Sir Robert Francis Transcript 8 May 2025 p84 INQY1000284

[382] James Quinault Transcript 8 May 2025 p143 INQY1000284

"*likely to have been written by IBCA staff themselves on the basis of their own understanding of the Regulations.*"[383]

Whilst I accept the evidence that the email itself was drafted internally within IBCA without input from the Cabinet Office, in circumstances where

(a) IBCA has worked "*with the Cabinet Office policy team to ensure that we understand in depth the policy intent behind each regulation – and from the perspective of operationalising them*";[384]

(b) the Cabinet Office "*has provided extensive advice to IBCA on the development and interpretation of the Regulations, on both specific regulations, and on the Regulations taken as a whole*";[385]

(c) between 21 March and 22 April 2025 IBCA sought and received advice from the Cabinet Office Legal Advisers on this issue;[386]

(d) the email is described as being based on "*current legal advice*"; and

(e) there has been no other explanation advanced by the Cabinet Office, as to why Regulation 3 has been drafted in the way that it has;

it is reasonable to assume that what is set out in the claim manager's email of 22 April 2025 does indeed reflect (or at the very least cast light on) the Government's reasoning.

That reasoning is fundamentally flawed, for two principal reasons.

The first is that it is based (or purportedly based) on "the legal test for liability". Yet the Government's decision to pay compensation has **never** been expressed to be on the basis of legal liability. Its acceptance was of the **moral** case for compensation. Where the scheme is founded on a moral responsibility to compensate, it is (as submitted on behalf of the core participants represented by Milners Solicitors) "*bizarre and illogical for the Government to then seek to limit eligibility based on concepts of liability and foreseeability.*"[387]

The second is that the reasoning is based on a false premise – namely, what the Government knew or ought to have known **about HIV**. It thus completely misunderstands (or ignores) the central fact that the blood and blood products in use before 1 January 1982 were already known to carry a risk of a dangerous virus – Hepatitis. There were, as detailed in the Inquiry Report, multiple safety failures and/or missed opportunities **before** 1 January 1982. By way of example only, these included: the importation of commercial concentrates; the failure to achieve self-sufficiency; increased pool sizes; unsafe treatment practices (relating both to

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[383] Third Written Statement of James Quinault para 56 WITN7755006

[384] IBCA Lessons Learned from early compensation claims 2 May 2025 para 1b WITN7757020

[385] Third Written Statement of James Quinault para 7 WITN7755006

[386] See the IBCA Policy Forum Minutes referred to above. IBCA Policy Forum Minutes 21 March 2025 Item 2 WITN7757014, IBCA Policy Forum Minutes 22 April 2025 Item 3 WITN7757015

[387] Written Submissions on behalf of the core participants represented by Milners Solicitors 23 May 2025 para 14i SUBS0000086

treatment with blood products and with blood), with people being treated unnecessarily or excessively; unsatisfactory donor practices; the continued collection of blood from prisons; and the failures to warn people of the risks of treatment with blood or blood products. All this should have been evident from even a cursory reading of the bullet points listed in the first few pages of the Inquiry Report Summary.[388] It is no answer to the moral case for compensation to say that it was only on 1 January 1982 that the Government should have foreseen the risk of HIV transmission and taken precautionary action: the risk of treatment **with blood and blood products** was there to be seen **before** 1 January 1982 and the Inquiry Report makes clear that action could and should have been taken – findings which, as the Inquiry understands it, the Government has accepted.

Moreover, the suggestion that in tort law an infection by HIV before 1 January 1982 was unforeseeable is questionable. As explained in the Inquiry Report it was well known since at least the Second World War that transfusions of blood and plasma could transmit Hepatitis, and from 1952 at the latest that measures could be taken which would go some way to protect against the risk. It was also known in theory that blood transfused from one person to another might transmit infections which the one had to that other, who until the transfusion had been free of it. But this was not only appreciated in theory. Experience in the 1970s had shown that serum hepatitis was caused not just by what had become known, and at least by 1972 become potentially identifiable, as Hepatitis B, but also by another virus or viruses which was neither Hepatitis A nor Hepatitis B. In short, both theory and experience was that blood could carry viruses that could cause serious harm yet which science could not yet specifically identify. The risks of both Hepatitis B and of the virus or viruses which caused what was labelled non-A non-B Hepatitis were sufficient in themselves to require protective measures to be taken to lessen or avoid the risk. What was stated as being a general principle, applied by the Privy Council in the leading case known as *The Wagon Mound No. 2*, was that "*a person must be regarded as negligent if he does not take steps to eliminate a risk which he knows or ought to know is a real risk and not a mere possibility which would never influence the mind of a reasonable man*."[389]

The exclusion of people infected with HIV through blood and blood products before 1 January 1982 from eligibility under the compensation scheme is thus both illogical and profoundly unjust.[390] It must be remedied through an amendment to the Regulations as soon as possible to remove the reference to 1 January 1982.

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[388] Infected Blood Inquiry Report 20 May 2024 Volume 1 pp3-6 INQY0001001

[389] [1967] 1 AC 617, [1966] UKPC 10 at p8; Lord Reid gave the judgment of the board. And see *Hughes v Lord Advocate* [1963] AC 837, [1963] UKHL 8, which is to the effect that it is no defence to liability that the danger materialising is not identical with the danger reasonably foreseen and guarded against (per Lord Reid), and that "*a defender is liable, although the damage may be a good deal greater in extent than was foreseeable. He can only escape liability if the damage can be regarded as differing in kind from what was foreseeable*" (per Lord Jenkins). Though Hepatitis and HIV are plainly not identical, it is difficult to regard the consequences of transmission of the HIV virus as being in a different class to the consequences of transmission of Hepatitis.

[390] An example is hardly needed, but developing an example Counsel to the Inquiry put to Nick Thomas-Symonds in questioning, if the interpretation advanced in the email were correct it would mean that a child with mild haemophilia who was treated once with imported factor concentrate before 1982, and

Nick Thomas-Symonds, when asked about this issue on 7 May 2025, said that because he understood "*precisely the point you are putting to me I say to the Inquiry that I am more than happy to take that point away because I understand exactly what you are referring to.*"[391] The Inquiry has received no further information from the Government, and it is disappointing to note that the issue was not addressed in the Minister's statement to Parliament on 14 May 2025.[392]

Although the root of the problem here lies in the drafting of the Regulations, and in the flawed policy intent behind that drafting, for which the Cabinet Office is responsible, I make two further observations.

The first is that the way in which this issue has come to light illustrates the fundamental importance of consultation both with people infected and affected and their legal representatives. As set out above, such limited information as was produced by the Cabinet Office before the 2024 Regulations were made included no reference to this matter. It was not an issue on which there was any consultation whatsoever. It has come to light only because the claim manager (rightly) sought to explain IBCA's understanding of the position to an applicant, and that applicant's legal representative then brought the exchange to the attention of Counsel to the Inquiry, thus enabling the issue to be explored during the Inquiry hearings in May 2025.

The second is that it is disappointing to note IBCA's stance, as relayed in David Foley's statements, that it is not part of IBCA's role to take a position on a matter such as this. Whilst decisions on the policy framework for the compensation scheme are ultimately a matter for the Cabinet Office, this is such an obvious anomaly – such an obvious case of injustice – that I do not understand why IBCA did not raise the matter promptly with the Cabinet Office.

One mother eloquently describes the injustice:

> "*My daughter has now been 'invited' to claim compensation only to be told by IBCA that she is likely to be ineligible because she was infected prior to 1982 ... The relevant regulation appears to have no regard for the fact that she is already registered with EIBSS, receives regular support payments and was awarded both interim compensation payments without question. To reach this stage of the proceedings to be faced with the unbearable possibility of her claim being declined is yet another nightmare to be somehow endured ... This unbearable and intolerable situation is cruel and unjust*".[393]

I recommend that: An amendment to the Regulations be made as soon as possible to remove the reference to 1 January 1982 from Regulation 3.

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because the condition was mild was not treated thereafter but who developed AIDS in consequence of the treatment, would be excluded from remedy.

[391] Nick Thomas-Symonds Transcript 7 May 2025 p152 INQY1000283

[392] Hansard Statement to Parliament by the Paymaster General 14 May 2025 pp1-2 RLIT0002464

[393] Letter from ANON to Sir Brian Langstaff 4 June 2025 WITN7770001

5 Hepatitis

This chapter looks at three principal issues which have arisen in respect of the way the scheme has treated Hepatitis. All relate to whether it does so fairly.

The scheme is a tariff scheme. If it pays the same sum both to someone whose injury is significantly less severe than that of another, and to that other, then the differences in severity will not be properly reflected in the payment. This will seem unjust to many.

Submissions have been made to the Inquiry that as it stands there is too large a gap between Level 2 (Chronic Hepatitis B or C) and Level 3 (cirrhosis).[394] This chapter addresses the question whether it is proper to recommend that the gap be closed, or that an intermediate level be recognised.

It begins with an account of how each of the national support schemes[395] identified an intermediate level, yet the compensation scheme has reached a position where it does not do so. It looks next at whether, separately, sufficient consideration has been given to the effects and consequences of the earlier treatments for Hepatitis B and C involving interferon. Then it examines whether in any event sufficient note has been taken of the extra-hepatic manifestations of Hepatitis C. Finally it considers whether the legislative definition of Level 3 has in any event been correctly understood and applied in practice.

It ends by asking, in the light of the evidence, what if any recommendations are justified.

The Special Category Mechanism and equivalents

One of the principal concerns that has been expressed about the compensation scheme relates to what has happened to the Special Category Mechanism ("SCM") – the term used by the England Infected Blood Support Scheme – and its equivalent under the other national schemes.[396] For ease of reference this report refers generally to the SCM but encompasses the position under each of the national schemes.

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[394] These Levels are set out in schedule 1 to the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p88 RLIT0002944

[395] England Infected Blood Support Scheme (EIBSS), Scottish Infected Blood Support Scheme (SIBSS), Wales Infected Blood Support Scheme (WIBSS) and Infected Blood Payment Scheme Northern Ireland (IBPS NI).

[396] See for example Counsel Presentation on Evidence concerning compensation 29 April 2025 para 29 INQY0000464. See further the Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) paras 2.45-2.47 SUBS0000084, Written Submissions on behalf of the core participants represented by Milners Solicitors paras 75-92 SUBS0000086, Written Submissions on behalf of the core participants represented by Watkins & Gunn para 7 SUBS0000091, Written Submissions on Compensation and IBCA on behalf of the Haemophilia Society para 7.14 SUBS0000087, Written Submissions on behalf of the core participants represented by Leigh Day para 38 SUBS0000088, Written Submissions made on behalf of the core participants represented by Collins Solicitors paras 36-41 SUBS0000092

The position under the four national support schemes

The origin of the SCM can be traced to the report of the Financial Review Group in Scotland in 2015, which recommended that:

> "*The current thresholds for Stage 1 and Stage 2 of the Skipton Fund should be the subject of a specific, evidence-based review to create new criteria based on health impact, rather than focusing predominantly on liver damage.*"[397]

Following the Department of Health's 2016 consultation on reform of the Alliance House Organisations, the Department proposed, and undertook a specific consultation on, the new Special Category Mechanism:

> "*The SCM will be a significant new element of the infected blood reforms. We now wish to consult with beneficiaries and other interested stakeholders on the details of the new SCM … The SCM proposal is aimed to benefit beneficiaries with hepatitis C stage 1 who consider their infection, or its treatment, has a substantial and long-term adverse impact on their ability to carry out routine daily activities. We anticipate that a significant proportion of the stage 1 beneficiaries will benefit from this new process and the higher annual payment level it would offer successful applicants, equivalent to the annual payment received by beneficiaries with hepatitis C who have stage 2 disease (that is, advanced liver disease such as cirrhosis and its complications) or those infected with HIV.*"[398]

In its response to the consultation, the Department of Health announced that the SCM would be introduced from November 2017 "*to enable people with a stage 1 infection that's having a substantial and long-term negative impact on their daily lives to apply for the higher annual payments received by those with HIV or stage 2 hepatitis C infection.*"[399] This was intended to offer "*greater fairness*" to people who experience "*substantial and long-term adverse impact to their health.*"[400]

In May 2018 the Clinical Review undertaken in Scotland recommended self-declaration:

> "*People … should be asked to self-declare hepatitis C impact in the following simple way … If they themselves considered that their (or their spouse's/partner's) hepatitis C had seriously affected and continued to affect their life, they would be eligible for a chronic HCV award at a higher level.*"[401]

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[397] Financial Review Group Final Report 17 December 2015 p5 WITN4081028

[398] Department of Health *Infected Blood: Consultation on Special Category Mechanism and Financial and Other Support in England* 6 March 2017 p5 WITN4688037

[399] Department of Health *Infected Blood: Government Response to Consultation on Special Category Mechanism and Other Support in England 28* September 2017 p5 DHSC0050134

[400] Department of Health *Infected Blood: Government Response to Consultation on Special Category Mechanism and Other Support in England* 28 September 2017 p17 DHSC0050134

[401] Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 p43 GGCL0000168

This approach was regarded by the Clinical Review Group as "*optimal*" because:

> "*It has patient and healthcare professional support, it is simple to administer, it aims to ensure that those with the greatest need receive the greatest benefit, it avoids patient/healthcare professional conflict and any need for an appeals process, it reduces stress among applicants to a minimum, it is person-centred recognising that the individual's perception of hepatitis C is critical, it promotes both individual and collective responsibility and it sends out a loud and clear message saying "you are trusted to make the appropriate declaration".*"[402]

Bill Wright, referring to the Financial and Clinical Review Groups, told the Inquiry: "*I felt that the voices of the infected and affected had, for once, been listened to.*"[403]

Self-declaration was implemented in Scotland in December 2018. Sir Robert Francis reported in his Compensation Study in 2022 that "*The experience of the Scottish support scheme suggests that generally applicants do their honest best to provide accurate information.*"[404]

In April 2019 the Wales Infected Blood Support Scheme introduced the Enhanced Hepatitis stage 1+ payment for people experiencing significant mental health issues or post-traumatic stress related to their infection which were affecting their ability to carry out day-to-day activities. Applicants self-certified and received the same annual payment as those who were eligible for the Stage 2 payment.[405]

In March 2021 the then Paymaster General Penny Mordaunt announced changes to the schemes to reduce disparities between them, including a commitment in Northern Ireland to introduce an SCM equivalent.[406]

It follows that England, Scotland, Wales and Northern Ireland had all recognised, in the light of experience, that to have a scheme which moved from one level of support payment (chronic infection with Hepatitis C) to a second (cirrhosis) without any intermediate level left too wide a gulf to do justice. Untreated Hepatitis C is progressive; the early treatment of it was particularly hard to bear and gruelling, and then in most cases to find after 48 weeks treatment that it had been ineffective could be soul-destroying.[407] Further, whereas early in

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[402] Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government May 2018 p44 GGCL0000168

[403] Third Written Statement of William Wright para 20.42 WITN2287019

[404] Infected Blood Compensation Study *Compensation and Redress for the Victims of Infected Blood – Recommendations for a Framework* 14 March 2022 p132 RLIT0001129. See also Sir Robert Francis Transcript 11 July 2022 p89, p128 INQY1000224

[405] Infected Blood Inquiry Report 20 May 2024 Volume 6 pp326-7 INQY0001006

[406] Statement to UK Parliament by Penny Mordaunt 25 March 2021 p2 WITN4066017,Infected Blood Inquiry Report 20 May 2024 Volume 6 pp331-333 INQY0001006

[407] An example is that of Glenn Wilkinson: "*I have been on treatment with interferon and ribavirin 5 times since 1995 and each treatment has had a devastating effect on both my physical and psychological health. On my second round of treatment I was put on a double dose interferon drug trial without being informed, which was devastating in its own right as I became extremely ill very quickly and didn't know why until I found out by chance that I had been put on a drug trial. The damage caused by these treatments has, and continues to have, long-term consequences, none of which have been adequately recognised. How can someone in my position receive the same level of compensation as someone that has either achieved SVR naturally, or has only ever received the newer direct-acting anti-retrovirals*

infections symptoms can be mild, as time goes by they become increasingly problematic and disabling.[408] Accordingly the SCM and its equivalents in the other three nations were introduced.

The position under the Infected Blood Compensation Scheme

The Government's proposals May 2024

The compensation proposals published (for the first time) by the Government on 21 May 2024, and described as reflecting the advice of the Expert Group, described infection severity bands for Hepatitis in the following terms:

> "*Infection severity banding for the Scheme has been designed in line with clinical diagnostic markers. This means that in most cases, applicants will know (or easily be able to identify from medical notes) the severity banding relevant to their application without needing to provide large volumes of medical evidence.*"[409]

The indicative bands for Hepatitis were:

> "*Hepatitis C or Hepatitis B – Chronic*
>
> *Hepatitis C or Hepatitis B – Cirrhosis (liver damage)*
>
> *Hepatitis C or Hepatitis B – Decompensated cirrhosis and/or liver cancer and/or liver transplantation.*"[410]

Severity banding would be used to calculate compensation awards for people infected.[411]

(DAAs), there is no comparison." Written Submission by Glenn Wilkinson pp2-3 SUBS0000085. Early interferon treatments were such that even after a 48 week course with all its side effects only about 1 in 5 people with genotypes 1 and 3 (accounting for some 80% of infections in the UK) managed to clear the virus from their system: that rate improved a bit over time such that it can be summarised by saying that over the period of some twenty years when interferon, then interferon with ribavirin and later pegylated interferon with or without ribavirin were used only a minority of those infected with the more common genotypes managed to clear the virus. It must be remembered that this describes the period as a whole, during which success rates improved very considerably, such that by its end just over half of those with genotype 1 and more than 4 out of 5 with genotype 3 cleared the virus. See Figure 15.13b in the Expert Report, bearing in mind the evidence that in the UK the proportions of those with genotype 1 and genotype 3 were broadly equal. Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 Figure 15.13b, p5 EXPG0000001, Hepatitis Expert Panel Transcript 26 February 2020 pp126-127 INQY1000052

[408] The evidence of the Hepatitis Expert Group to the Inquiry was that where Hepatitis C infection became chronic, then if untreated it would develop slowly but progressively – after 20 years approximately 30% would have developed cirrhosis; after 30 years 40%. "*Estimates of the rate of progression from infection to cirrhosis vary widely, but have been estimated at 1-2%/year, with approximately 20-30% with cirrhosis after 20 years (but estimates range from 2-40% in different studies) and 40% at 30 years … Successful treatment for HCV can considerably reduce (by approximately 70%), but not eliminate, the risk of cancer.*" Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p28 EXPG0000001

[409] Infected Blood Compensation Scheme Proposal Summary 21 May 2024 p13 RLIT0002493

[410] Infected Blood Compensation Scheme Proposal Summary 21 May 2024 p13 RLIT0002493

[411] Infected Blood Compensation Scheme Proposal Summary 21 May 2024 p5, p13 RLIT0002493

The Expert Group, which had not consulted (or even met with) people infected and affected, explained in its Interim Report that:

> "*These bandings are based on clinical markers.*[412] *The Expert Group considered that it was important to ensure that the evidence required from people claiming their right to compensation should be readily available from them, be verifiable in order to enable objective assessment of their entitlement, be proportionate to the need to operate the scheme and that inappropriate intrusive questions should be avoided.*"[413]

The Cabinet Office's unpublished Engagement Explainer repeated this explanation:

> "*The Expert Group recommended that the severity bandings were designed using clinical markers (i.e. recognised diagnoses)*[414] *so that people would have readily available the evidence required to demonstrate the severity of their infection. This means that in most cases people applying to the Scheme will know or should be able to identify from medical records which severity band they fall under. This will avoid the need for intrusive questions and/or large amounts of evidence to be provided to the Scheme.*"[415]

There is thus no reference to the SCM or equivalent in the proposals formulated, and the material published, in May 2024.[416]

<u>Concerns raised during the June 2024 engagement</u>

The omission of the SCM (or equivalent) from the Government's proposals met with consternation and concern. Legal representatives pointed out that:

> "*a person chronically infected with HCV and admitted to the SCM has been so admitted because the IBSS have recognised that the totality of the impact of their infection was so severe that it has, in large part, rendered them unable to work.*"[417]

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[412] A clinical marker is a feature of a condition, illness or infection which can be determined objectively eg by measurement or by specific testing, and shows that the patient probably has the illness, condition or infection in question.

[413] Infected Blood Inquiry Response Expert Group Interim Report 21 May 2024 p6 RLIT0002478

[414] Technically speaking, a marker is not a diagnosis (see previous footnote) - a diagnosis is a conclusion as to what the available evidence, including clinical markers, indicate. The sense of the explanation is however clear.

[415] Infected Blood Compensation Scheme Engagement Explainer June 2024 p10 WITN7752004

[416] The minutes of the meeting of the Expert Group cast no light on its thinking on this issue. There is one brief, and less than clear, reference to the SCM in the Group's meeting on 19 April 2024 where the minutes record (under the heading "*Reflections on draft slides for Ministers*") "*Reflecting on the difference between HIV and Hepatitis C, and the level of impact on financial loss for those who have been infected for a long-time or since childhood this may not be reflected in the current framework. ACTION:- To be reflected in the supplemental process, utilising existing evidence e.g. Special Category Mechanism status under EIBSS where possible.*" Minutes of the Infected Blood Inquiry Response Expert Group 19 April 2024 p29 CABO0000925

[417] Response to engagement exercise by Sir Robert Francis KC from Milners Solicitors 28 June 2024 p4 WITN7752005. See also from Collins Solicitors: "*there is concern that the severity bandings are a blunt*

And that:

> "*… the method of categorising the tariff which should be applied for HCV infection based on the extent of liver damage is too crude. Evidence heard by the Inquiry shows this. The original Skipton criteria were based on liver damage as the sole touchstone of loss. Governments across the UK later revised the terms of the support schemes to reflect developments in understanding with the stage 1 and 2 categories being abandoned, self-assessment being adopted and the difference between severe stage 1 and stage 2 infection eventually being eradicated under the SIBSS. Without suitable refinement to take account of the non-liver associated sequelae (which are clearly documented and could be categorised in the evidence heard by the Inquiry) there is a significant danger that the loss associated with infection and its consequences will be incorrectly diagnosed.*"[418]

The Haemophilia Society pointed out that "*The Special Category Mechanism (SCM) in England, and equivalents in other parts of the UK, is utilised by the support schemes to identify those people who have suffered a level of impact which has affected peoples' ability to work and carry out normal daily living. This has been overlooked by the compensation framework.*"[419]

In his report of 12 July 2024, Sir Robert Francis considered the omission of the SCM from the banding:

> "*many contributors have commented that the suggested bandings do not align or appear to take account of the Special Category Mechanism [SCM] which has been introduced into all support schemes; albeit with differing criteria in each nation. In its written submissions, one representative organisation supported this concern by reference to its survey in which some 55% of respondents wanted to see a banding for additional day-day banding,* [sic] *for example the SCM. In the course of the meetings, Sir Jonathan Montgomery undertook to take this point back to the expert group for consideration.*

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tool which may not accurately reflect the realities of people's individual conditions and will need to be more nuanced and/or flexible in approach" and from Leigh Day: "*The SCM payments enabled individuals infected with HCV who suffer from specific conditions and/or side effects from HCV treatment to apply for higher annual payments equivalent to payments made to individuals infected with HIV and those warded HCV stage 2 annual payments.*" Response to engagement exercise by Sir Robert Francis KC from Collins Solicitors 26 June 2024 p2 WITN7763011, Response to engagement exercise by Sir Robert Francis KC from Leigh Day 28 June 2024 p14 WITN7762003

[418] Response to engagement exercise by Sir Robert Francis KC from Thompsons Solicitors (Scotland) 28 June 2024 para 25 WITN7760003. See also from Watkins & Gunn: "*we echo the representations of the other RLRs as the prescriptive nature of the bands we have had sight of. They lack detail and nuance … A lesson we learned from taking the witness statements of c300 infected blood victims is that the impact on people/families of treatment for their infections cannot be overstated and in some cases was more severe than the infection itself. Also, the psychological/psychiatric impact of the treatments received was in many cases life changing.*" Response to engagement exercise by Sir Robert Francis KC from Watkins & Gunn 28 June 2024 paras 16-17 WITN7761002

[419] Response to engagement exercise by Sir Robert Francis KC from the Haemophilia Society June 2024 p13 WITN6392290

> *I believe that he intends to recommend that those with conditions as defined in SCM criteria should be recognised as a distinct severity band, or to add more explicit criteria to the existing bands where this is more appropriate.*
>
> *I agree that there is a strong case both in terms of ensuring the severity bands reflect as a minimum the criteria for support payments, and to avoid supplementary applications being made because of the omission of this category. This is an area in which both I and the Government will be dependent on the expert advice.*
>
> *I understand that the expert group is to advise that for those who were eligible for an award under a Special Category Mechanism in one of the support schemes should be eligible for an enhanced care award under a bespoke supplementary category. In the case of applicants who have not been in receipt of a support payment, they would qualify for an enhanced award if they can show they would have met the criteria for the SCM in their country. The expert group considers that this is the fairest way to reflect the purpose of the SCM as being to support particular needs rather than because their infection of resulting symptoms are different from those reflected in the injury impact awards. While the acceptability of this solution to applicants will depend on the actual figures offered, as an approach I would consider this to be a fair one.*"[420]

His recommendation was that "*the advice of the expert group is followed with regard to the recognition of SCM eligibility.*"[421]

It is plain from the context that the advice of the Expert Group which Sir Robert was recommending should be followed by the Government was the new advice which he understood the Expert Group would be proffering (the Group having apparently omitted to consider the SCM previously): namely that there should be an enhanced award reflecting the criteria in the current support schemes.

The Expert Group's Final Report and the details of the scheme announced in August 2024

In its Final Report the Expert Group explained that it had "*reflected on the feedback that insufficient recognition was given to the impact that some victims experienced*" and revised its advice.[422] Under the heading "*Enhanced, Advanced and 'Special Category' bands*" the Group explained that:

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[420] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 pp31-32 RLIT0002466. The Expert Group considered this issue at its meeting on 4 July 2024, the minutes of which record that the group "*discussed eligibility of those currently with the Special Category Mechanism (SCM). The Chair suggested that the working assumption should be that those with SCM would be passported so they did not need new evidence. The rest of the route would be the small number of people that have not already come forward to the schemes.*" Minutes of the Infected Blood Inquiry Response Expert Group 4 July 2024 p40 CABO0000925

[421] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p32 RLIT0002466

[422] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 p7 RLIT0002474

> "*Feedback from the engagement meetings has prompted us to review the need for an additional banding to reflect the greater impact that some people with HCV have experienced. We therefore reviewed the criteria used in the four national Infected Blood Support schemes where beneficiaries have shown that there has been a greater than average impact on them of chronic HCV or complications of their disease (Annex B). These are similar but not identical. The Expert Group has considered the equivalent features in relation to HBV, not currently within the scope of the support schemes and also whether they should be recognised in relation to HIV.*
>
> *Some of these aspects of people's experience 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. 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. This should take the form of a supplementary route application and have the adjustments set out below. Those who have already been recognised as qualifying for the enhanced payment categories under the Support Schemes would not need to produce further evidence to qualify.*
>
> *The Expert Group did consider whether there should be different injury award bandings for these categories but considers that they are best understood as uncommon consequences of the same injuries rather than separate severity bands attracting a different level of injury award. It does not therefore advise any changes to the injury, autonomy or social impact awards for people in the supplementary health impact groups.*"[423]

The Final Report then set out tables defining "*the enhanced, advanced and special category bands.*" Six health impact groups were set out, of which the fifth was as follows:

> "*5) Other Hepatitis C*[424] *associated extra hepatic disorders resulting in long term severe disability. This includes those currently assessed as the following category on IBSS:*
>
> - *Hepatitis Special Category Mechanism (EIBSS)*
> - *'Severely Affected' Hepatitis C (SIBSS)*
> - *Hepatitis C Stage 1 Plus (WIBSS)*
> - *Hepatitis C Stage 1 Enhanced Payments (NIIBSS)*[425]

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[423] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 pp26-27 RLIT0002474

[424] The adjacent column indicated that this would apply to people infected with Hepatitis B and Hepatitis C.

[425] Annex 2 set out the criteria used in the support schemes. Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 pp83-86 RLIT0002474

> *For new applicants not currently registered on support schemes, you may be eligible if due to the impact of Hepatitis C and/or its treatment you:*
>
> *(i) Have autoimmune disease due to or worsened by interferon treatment for hepatitis C, for example: Coombes positive haemolytic anaemia; Idiopathic fibrosing alveolitis of the lung; Rheumatoid arthritis.*
>
> *(ii) have sporadic porphyria cutanea tarda causing photo sensitivity with blistering.*
>
> *(iii) have immune thrombocytopenic purpura.*
>
> *(iv) have type 2 or 3 mixed cryoglobulinaemia which is accompanied by: Cerebral Vasculitis, Dermal Vasculitis, Peripheral neuropathy with neuropathic pain.*
>
> *(v) you are suffering from significant mental health problems, persistent fatigue and/or other health and wellbeing impacts due to Hepatitis C infection as a result of infected blood/ blood products, which affect your ability to perform daily tasks. This may include:*
>
> - *You are unable to work or have had to reduce your working hours or change your working pattern due to the impact of physical or mental health problems.*
> - *You had to leave a better job, role or career due to physical or mental health problems.*
> - *Your mental health problems have directly resulted in the breakdown of your marriage or other long-term relationship and this is still having significant effect on your life.*
> - *Your mental health problems frequently make it very difficult for you to leave your home or socialise with other people.*
> - *You are unable to carry out day to day activities e.g. shopping, cooking, gardening or cleaning.*"

The table recorded recommended amendments to the care award and to the financial loss award. It stated that "*Those registered with SCM in the current support scheme would automatically be accepted*" and that "*New applicants would need to provide evidence supporting diagnosis and impact.*"[426]

The Government's update, published on 16 August 2024, reported that the Government had accepted 69 of Sir Robert's 74 recommendations.[427] With respect to the SCM, the update stated:

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[426] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 pp30-33 RLIT0002474

[427] Government Update on the Infected Blood Compensation Scheme 16 August 2024 p3 WITN7760006

> "*Following the recommendations of Sir Robert and advice from the Infected Blood Inquiry Response Expert Group, the Scheme will now include a 'health impact' supplementary route to compensation. This will provide more financial support for infected people with health conditions not recognised within the core route that could impact an applicant's care requirements and capacity to earn. This will include impacts currently recognised under the Infected Blood Support Scheme payment band 'Hepatitis Special Category Mechanism' (or equivalent UK wide bands).*"[428]

On 23 August 2024 (the day the 2024 Regulations were made and came into force) the Government published a policy paper providing more detail about the scheme. Under the heading "*Additional awards available through the Supplementary Route*", this paper described the "*Health Impact supplementary sub-route*" in the following terms:

> "*Applicants will need to provide evidence of specific health impacts or conditions (listed below, and detailed at Annex C) for which additional tariff-based compensation will be awarded. Where an applicant can demonstrate a qualifying health condition, it will not be necessary to provide any further evidence of financial loss and/or care costs.*
>
> *Health impacts relating to HIV, Hepatitis B or Hepatitis C infections that may qualify an applicant for higher Financial Loss and/or Care awards through the Health Impact supplementary sub-route are:*
>
> - *Severe visual impairment*
> - *Neurological disorders resulting in long-term severe physical or mobility disability (e.g. cerebral toxoplasmosis resulting in severe stroke)*
> - *Neurological disorders resulting in long-term neurocognitive impairment (e.g. HIV-associated dementia; chronic hepatic encephalopathy related to Hepatitis C/B)*
> - *Severe psychiatric disorders (e.g. diagnosed psychiatric disorders requiring inpatient care or prolonged psychiatric treatment under the care of specialist mental health services)*
> - *Other hepatic disorders caused by Hepatitis B or Hepatitis C resulting in long-term severe disability*
> - *End-stage kidney disease requiring renal replacement therapy.*
>
> *Further detail on the qualifying health impacts listed above and the compensation available through the Supplementary Route are provided in Annex C.*"[429]

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[428] Government Update on the Infected Blood Compensation Scheme 16 August 2024 p6 WITN7760006

[429] Infected Blood Compensation Scheme Summary 23 August 2024 pp27-28 RLIT0002945

Annex C to the paper described the "*Other Hepatitis-associated disorders*" in terms which match both what was in the Expert Group's Final Report and the criteria from the national support schemes. Thus, Annex C explained that:

> "*This includes people currently registered under the following IBSS categories:*
>
> *Hepatitis Special Category Mechanism (EIBSS)*
>
> *'Severely Affected' Hepatitis C (SIBBS)*
>
> *Hepatitis C Stage 1 Plus (WIBSS)*
>
> *Hepatitis C Stage 1 Enhanced Payments (NIIBSS)*
>
> *Applicants not currently registered with existing IBSS may be eligible if due to the impact of Hepatitis C or B and/or its treatment, they have any of the following:*
>
> *(i) autoimmune disease due to or worsened by interferon treatment for Hepatitis B or Hepatitis C. For example: Coombes positive haemolytic anaemia; Idiopathic fibrosing alveolitis of the lung; Rheumatoid arthritis;*
>
> *(ii) sporadic porphyria cutanea tarda causing photosensitivity with blistering;*
>
> *(iii) immune thrombocytopenic purpura;*
>
> *(iv) type 2 or 3 mixed cryoglobulinaemia accompanied by: cerebral vasculitis; dermal vasculitis; or peripheral neuropathy with neuropathic pain;*
>
> *(v) significant mental health problems, persistent fatigue and/or other health and wellbeing impacts, affecting the person's ability to perform daily tasks. Examples may include:*
>
> *An inability to work or a need to reduce working hours or change working patterns due to the impact of physical or mental health problems.*
>
> *A need to leave a better job, role or career due to physical or mental health problems.*
>
> *Mental health problems which have directly resulted in the breakdown of a marriage or other long-term relationship which is still having a significant effect on a person's life.*
>
> *Mental health problems which frequently make it very difficult to leave home or socialise*
>
> *An inability to carry out day to day activities e.g. shopping, cooking, gardening or cleaning.*"[430]

Hepatitis B is explicitly included in Annex C.

On 2 September 2024 the Minister gave a statement to Parliament confirming his acceptance of the majority of Sir Robert Francis' recommendations and recording the Government's recognition that "*the scheme will not cover every circumstances in the way an individual*

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[430] Infected Blood Compensation Scheme Summary 23 August 2024 pp50-52 RLIT0002945

assessment would, so in order to ensure that every applicant is justly compensated, we have introduced a health impact supplementary route for additional compensation." He explained that a second set of regulations would provide for (amongst other matters) claims under the supplementary route and that the Government's plans regarding that second set of regulations "*are in the documents available on gov.uk*" (ie those documents described above).[431]

Pausing there, it is therefore clear that as at the beginning of September 2024, and as a direct consequence of the feedback that had been given by people infected and affected during the June engagement, the Government had decided that (through the supplementary route) the scheme **would** compensate for the consequences of infection that had been captured in the SCM and its equivalents. It was clear that this would encompass not only those already recognised under the national support schemes but also new applicants not currently registered on the support schemes. This was acknowledged by Nick Thomas-Symonds in his oral evidence to the Inquiry on 7 May 2025:

> "*Q. As at 2 September, you published –*
>
> *A. Yes*
>
> *Q. – something which said that in the scheme there would be criteria that were the same as the SCM and equivalent schemes?*
>
> *A. That's exactly what was published.*"[432]

The Government's change of position in 2025

There the position rested – at least as far as people infected and affected were aware – until January 2025 when the Cabinet Office shared with campaign groups (but did not publish) a factsheet. This provided a summary of what was now referred to as the Severe Health Condition Award under the supplementary route:

> "*This award will be available to eligible infected people who have suffered from a specified rare severe health condition as a result of their infection that has not already been taken into account in the core awards (for example, severe visual impairment, and neurological disorders which result in long term severe physical disability).*
>
> *The list of eligible severe health conditions has been developed following advice from the Infected Blood Response Expert Group. The health conditions included are those that have clear clinical markers for which applicants will be able to provide specific evidence. The Scheme will therefore have different thresholds and eligibility requirements to the Infected Blood Support Schemes for the Severe Health Condition awards. The eligibility criteria that the Scheme uses for the Severe Health Condition Award will not change the value of regular*

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[431] Hansard Statement to Parliament by the Paymaster General 2 September 2024 pp2-3 RLIT0002464

[432] Nick Thomas-Symonds Transcript 7 May 2025 p158 INQY1000283

> *support scheme payments an IBSS beneficiary will continue to receive as part of their compensation package, if that is the option they choose. This will mean that IBSS beneficiaries will continue to receive 'Special Category Mechanism' (or equivalent IBSS category) payments without providing further evidence regardless of Severe Health Condition Award eligibility.*
>
> *However, this does mean that all applicants (regardless of IBSS eligibility) will need to show IBCA that they have one of the qualifying listed health conditions to be eligible for a Severe Health Condition Award through the Scheme's own supplementary route. Specifically, applicants will need to provide medical evidence of their specific health conditions. They may also need to provide evidence that the health impact or condition stopped them from working, and/or assessment of their care needs, to be eligible for supplementary care and financial loss awards."*[433]

This was the first indication that the position as set out in the Expert Group's Final Report and in the details of the scheme published by the Government in August 2024 was not going to be implemented. The consequence is that:

- anyone not registered with the support schemes (which will include people with Hepatitis B and anyone affected by the cut-off dates in the existing schemes) will not be eligible for the Severe Health Condition award without proving that they have a specified rare severe health condition as a result of the infection – and that what would have qualified them for an SCM award or its Scottish, Welsh or Northern Irish equivalent will be insufficient to meet this criterion.
- anyone who is registered and has been accepted as eligible under the existing support schemes is effectively forced to continue to receive the SCM or equivalent payments on an ongoing basis rather than lump sum compensation.[434]

It is notable that the factsheet fails to acknowledge that this represented a significant change of position on the part of the Government (still less provides an explanation for that change of position).

On 12 February 2025, when the 2025 Regulations were laid in draft, an Addendum Report from the Expert Group was published.[435] The Group stated that:

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[433] Draft Infected Blood Compensation Scheme Regulations 2025 Factsheet January 2025 pp6-7 WITN6392300. The same position was articulated in James Quinault's meeting with campaign groups in January 2025. Infected Blood Compensation Scheme: Meetings with Community Representative Groups 17-22 January 2025 p3 WITN0622014

[434] When this was put to the Expert Group under the Inquiry Rules 2006, Professor Montgomery explained that *"We did not intend for the advice we gave in our Addendum Report to force applicants into a decision … and considered it inappropriate to take those choices away from them."*

[435] The Addendum Report contains a foreword by the Minister for the Cabinet Office which states that "*The infected blood community must sit at the heart of the Infected Blood Compensation Scheme. The Infected Blood Inquiry and Sir Robert Francis reflected on the experience of the community to inform their recommendations, and these recommendations continue to form the basis of the Scheme … I hope this Addendum Report brings reassurance that the choices that I have made in the development of the regulations are fully informed by the knowledge and experience of the experts and the insights of the*

> "*We revised our initial advice in a number of respects based on the feedback from the engagement events convened by Sir Robert Francis KC as Interim Chair of the Infected Blood Compensation Authority. This revised advice was set out in our final report. Following their acceptance of the recommendations made by Sir Robert Francis, we were invited by the Government to provide further detailed advice on three issues in order to assist with the drawing up of the Scheme in a second set of regulations. We have been pleased to have the opportunity to consider these issues further, which we have done in light of the engagement meetings held by Sir Robert.*"[436]

The statement that the Group has considered these issues further "*in light of the engagement meetings held by Sir Robert*" is a curious one. It was those engagement meetings that had led the Group to produce the revised advice in its Final Report. It is puzzling to see the Group now reaching a different conclusion, without any further engagement, whilst suggesting that its further reconsideration has been undertaken "*in light of the engagement meetings*".

The Addendum Report continued:

> "*This addendum to our existing report offers advice on these issues, which are:*
>
> - *Supplementary 'Severe Health Condition' awards where the beneficiaries experience significantly greater loss of financial earnings and/or care needs than envisaged in the calculations that underpin core awards.*
>
> *...*
>
> *In formulating our advice on these supplementary awards, we have retained the fundamentals of the scheme that we described in our main report. In particular, that any evidence required should be:*
>
> - *Accessible to claimants (and assessors), so that only information that is reasonably expected to be available if requested;* [sic]
> - *Assessable, so that the relevant question about eligibility can be answered;*
> - *Verifiable, so the integrity of the scheme is maintained;*
> - *Proportionate to the need to answer the question to determine eligibility or quantify awards, so that:*
>   - *Privacy is maintained although applicants can be asked to consent to access to medical records if that would provide the evidence needed to establish their eligibility; and*

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community." Infected Blood Inquiry Response Expert Group Addendum to Final Report 12 February 2025 p4 WITN7762015. There is no recognition in this foreword of the fact that the change in August 2024 that was indeed expressly based on "*the insights of the community*" – the need for a continuation of the SCM and its equivalents in the new scheme – was now abandoned, without any engagement or consultation with the community at all. Nor was there an explanation in the updated Scheme Summary. Infected Blood Compensation Scheme Summary 31 March 2025 RLIT0002481

[436] Infected Blood Inquiry Response Expert Group Addendum to Final Report 12 February 2025 p5 WITN7762015

> – *Excessive detail is not sought that would be unnecessarily time consuming (leading to delay and expense in processing cases).*
>
> ***Severe Health Condition awards***
>
> *A key principle of the scheme is that clinical markers and diagnoses are used to identify severity bandings and to set step changes in compensation. We have approached Severe Health Condition awards with this in mind. We suggest that there are some conditions where the result of the infection or treatment of the infection would have had a greater impact than is reflected in the core award. Whilst these conditions may be rare, they should still be recognised within the scheme. We propose six groups of specific conditions where this would apply and suggest how the awards should be revised to account for their additional impact.*"[437]

The scope of the "*other Hepatitis-associated disorders*" that had fallen within the supplementary route as recommended in the Group's Final Report from August 2024 is then narrowed so as to exclude the category of "*significant mental health problems, persistent fatigue and/or other health and wellbeing impacts, affecting the person's ability to perform daily tasks.*" The explanation for this is:

> "*As the compensation scheme is based on clinical markers that will be accessible, assessable and verifiable,* ***the Group does not think it is appropriate or proportionate to require applicants to make personal life impact statements****. It notes that applicants who currently receive enhanced awards under the existing support schemes will be able to choose to continue with those payments instead of taking the amounts that would be awarded for future years financial loss and care. This ensures that they are not disadvantaged by the approach we have taken.*"[438]

This is an unconvincing and somewhat startling explanation. This is a change, to the **disadvantage** of people infected, purportedly justified on the basis of a (non-clinical, non-expert) judgment by the Expert Group that it is not "*appropriate or proportionate*" to require applicants "*to make personal life impact statements*" without **any** recognition that the introduction of the SCM and equivalents in the support schemes had been a move that was welcomed[439] and without **any** attempt to consult with people infected and affected

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[437] Infected Blood Inquiry Response Expert Group Addendum to Final Report 12 February 2025 pp5-6 WITN7762015

[438] Emphasis added. Infected Blood Inquiry Response Expert Group Addendum to Final Report 12 February 2025 p15 WITN7762015

[439] This was accepted by the Minister in his oral evidence: "*Q. Were you aware that the SCM and its equivalents had been very hard fought for by the community? A. I was, yes. Q. And they had greatly valued it and one of the reasons they valued it is for the very reason the expert group disparages. It's because they were able to say for the first time to somebody in authority: let me tell you how this disease takes its toll on my life. In Scotland and I think in Wales there was a process of self-assessment which, as Sir Robert Francis has previously told this Inquiry, was successful. It did not result in fraudulent claims. So the decision that's been taken takes away one of the few successful and welcomed features of the previous schemes. Again, why? A. Well, I didn't read that as disparaging on the printed page but certainly*

to ascertain their views on this matter. It is an extraordinary about-turn by a group that had never directly consulted anyone infected, and contains an inaccurate statement about who their advice disadvantages (namely, anyone receiving SCM or equivalents who would wish to receive a lump sum, and anyone with Hepatitis B or not registered for the support schemes who would have been eligible for the supplementary health route set out in the August scheme summary).[440]

Nor is there any clear explanation of why it was that the Cabinet Office, having accepted the Expert Group's advice and the recommendation of Sir Robert Francis in August 2024, then decided to row back on it (and to do so without telling people infected and affected).

If the Government regarded it as essential that there should be objective clinical markers, and a Severe Health Condition award could not be made without them, it could and should have made that position clear in its earlier statements on the severe health conditions issue. In respect of the Severe Health Condition award for those with Hepatitis C this would be a return to the time before a special category mechanism was introduced in England, when it was seen that it was necessary to fill the stark gap between conditions which qualified for Stage 1 awards in the support schemes, and those which merited Stage 2. It would represent a departure from the approach taken by Westminster, Edinburgh, Cardiff and Belfast which was to introduce an SCM or equivalent approach in each jurisdiction. It would differ from the approach of the Expert Group in its advice hitherto. This was not however a clinical issue as set out in its latest report – the question was whether it was appropriate or not for individuals to make personal life impact statements. This was a policy question, and not one on which the Cabinet Office needed clinical advice. Yet the decision appears to have been made on the basis that the Expert Group had now advised it.

A question was asked of the Minister in the Delegated Legislation Committee on 24 March 2025 regarding the SCM, but the answer ("*… the impact of a hepatitis infection can obviously range from very mild to very severe … The expert group … provided the Government with clinical advice on the distinctions between those impacts. That meant that we could set severity bands for hepatitis based on clear clinical markers. Therefore, where someone's experience of hepatitis – whether historical or now – has been more severe, they will get*

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your point about the great battle that so many people went through around Special Category Mechanism, I absolutely recognise." Nick Thomas-Symonds Transcript 7 May 2025 pp165-166 INQY1000283

[440] When this was put to the Expert Group under the Inquiry Rules 2006 Professor Montgomery stated that in developing the Severe Health Conditions as set out in the Addendum Report "*The intention of the Expert Group was not to remove any conditions but to provide further and clearer definitions of those conditions that would qualify, adding any that had not been included in our Final Report.*" He explained that "*Our intention when we developed our advice on the health impact groups and when we gave further, more detailed, advice in our Addendum Report, was that all the infected who would have qualified for SCM or its equivalents support payments would receive comparable or greater compensation under the compensation scheme, through a combination of the core award and a supplementary award where necessary.*" Dr Elsharkawy also confirmed that the descriptions in the Addendum Report "*were not intended to exclude any applicant who had previously been awarded an SCM or equivalent payment or any new applicant who would have qualified for one.*" If this was the intention of the Expert Group, this intention was not realised in the scheme as set out by the Government in the 2025 Regulations.

more compensation")[441] does not address the fact that there has been a change of position on the part of the Government.

It is necessary therefore to look at the evidence given to this Inquiry in order to try to better understand the Government's about-turn. The position is unsatisfactorily addressed in James Quinault's second written statement of 3 April 2025.[442] The explanation offered is that "*The Compensation Scheme core route tariffs already take into account the health conditions that infected people are most likely to experience as a result of their infection*", that "*some*" of the impacts which the SCM and equivalents are intended to reflect are already recognised under the core award, including significant psychological impact and chronic fatigue affecting people's ability to earn, and that "*this is why the Severe Health Condition route does not match SCM or its equivalents.*"[443] The statement continues by suggesting that the criteria in the SCM and equivalent schemes are not "*based on clear clinical markers which could be used to set step changes in compensation under the Scheme.*"[444] However, it is plainly possible to devise a scheme of banding that uses the SCM criteria – that is exactly how the national support schemes have successfully operated. Surprisingly the statement does not acknowledge or explain the change in the policy paper from August to February, nor the change in the advice of the Expert Group, nor the fact that the Government has turned its back on something which it committed to do in August 2024. There must, rationally, be some explanation: but it was missing from what he said.

The Minister in his oral evidence to the Inquiry suggested two reasons. He said "*there isn't a perfect cross-over in the scheme between Special Category Mechanism conditions into the supplemental health route*" because "*certain conditions that meant that people were on the Special Category Mechanism in the support schemes … were already taken into account in the core route … something like chronic fatigue, for example, which clearly would affect people's ability to work.*"[445] He explained that the logic behind the decision was "*to have that single qualifying standard of clinical markers across those registered and those not.*"[446] The difficulty with this reasoning is two-fold. First, if the purpose is to achieve equality or consistency between those registered and those not, the Government's change of position in fact achieves the opposite. It leaves those registered able to continue to receive SCM

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[441] Hansard Delegated Legislation Committee Debate on the Draft Infected Blood Compensation Scheme Regulations 2025 24 March 2025 p6 RLIT0002485

[442] Second Written Statement of James Quinault paras 127-147 WITN7755003

[443] Second Written Statement of James Quinault paras 130-131 WITN7755003

[444] Second Written Statement of James Quinault para 134 WITN7755003

[445] Nick Thomas-Symonds Transcript 7 May 2025 pp157-158 INQY1000283. He gave the same reason on 5 June 2025. "*Components of the SCM criteria are planned in both the core awards and the supplementary route.*" Hansard House of Commons Cabinet Office Oral Questions 5 June 2025 p2 RLIT0002968

[446] Nick Thomas-Symonds Transcript 7 May 2025 p166 INQY1000283. A further difficulty with this position is that it is clear from the minutes of the Expert Group's meeting on 10 July 2024 that the Group saw no difficulty with what it went on to recommend in its Final Report: "*A preference for the current supplementary route was expressed, whilst addressing that new entrants to the scheme would be likely to be rare. It was clarified that individuals that were receiving SCM currently would passport to this framework rather than having to demonstrate eligibility, whilst new participants would be subject to specific eligibility criteria, aligned with the financial loss associated with cirrhosis.*" Minutes of the Infected Blood Inquiry Response Expert Group 10 July 2024 p41 CABO0000925

payments (but not compensation in a lump sum), whilst preventing those unregistered from receiving any form of equivalent compensation. Secondly, it ignores the central fact that there are consequences of infection with, and treatment for, Hepatitis that cannot be captured by "*clinical markers*" – it was this which led to the devising of the SCM and its equivalents in the first place. Insistence on the presence of clear clinical markers means, in practice, that there are effects – seriously disabling and severe effects – which are all too real but which go unrecognised in the compensation scheme.

James Quinault's oral evidence to the Inquiry was that the advice of the Expert Group (in its Final Report of 16 August 2024) "*was ambiguous, as it turns out.*"[447] He was then asked about the Government's acceptance of that advice:

> "*SIR BRIAN LANGSTAFF: May I just ask this question. You say that the advice from the Expert Group was ambiguous. There was, as I understand it, no ambiguity at the time about the Government's acceptance of the need for something in between?*
>
> *A. … I acknowledge completely that anyone reading the section of that – of that section of the expert group's report, together with what the Government and Sir Robert would have said, would have assumed that this meant that everything in the current SCM would count.*
>
> *MS RICHARDS: They have assumed that because that's what it said in terms in the Government's 23 August publication.*
>
> *A. So what that said was that there would be a severe health impacts route, yes.*"[448]

The suggested ambiguity in the Expert Group's Final Report is identified in a further written statement from James Quinault:

> "*The Expert Group's final report was ambiguous about whether all of the extra-hepatic effects of hepatitis and its treatment that are covered by the SCM or its equivalents should also qualify for the severe health impacts route; or whether instead the Expert Group meant that only some of them should qualify, since their Report identifies some effects as already reflected in core awards under the scheme.*"[449]

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[447] He said: "*I don't think it was an about-turn by the expert group. I think their original advice was ambiguous, and I think they cleared it up in this direction rather than the other. I think it's unfortunate. I acknowledge the impact of that … might have been that people would … have been expecting one thing and then got another, but … that was not the intention.*" James Quinault Transcript 8 May 2025 p134 INQY1000284

[448] James Quinault Transcript 8 May 2025 pp127-128 INQY1000284. The paper published by the Government on 23 August 2024 noted that "*further work will be undertaken on the Supplementary Route ahead of laying the second set of regulations.*" Infected Blood Compensation Scheme Summary 23 August 2024 p47 RLIT0002945. This reference to "*further work*" would reasonably be understood as work to flesh out the details of that which was clearly stated to be part of the scheme, and not "*further work*" to remove elements of the scheme.

[449] Third Written Statement of James Quinault para 18 WITN7755006

The specific point of ambiguity, he argues, is "*whether the Expert Group intended that those in the SCM for chronic fatigue for example should also qualify automatically for the severe health impacts route even though this is compensated for under the core route.*"[450]

Chronic fatigue, though, was not a sufficient condition for SCM and equivalents.[451] The SCM and equivalents recognised the original gulf between chronic infection with Hepatitis C and cirrhosis had not been fair and yet the compensation scheme reinstates it. Thus as it currently is, people with chronic Hepatitis C receive 40% of the baseline for full annual earnings loss (which drops to 20% for each year after effective treatment was introduced (from 2017 onwards), whilst if they have cirrhosis the figure is set at 80% of the baseline figure (reducing to 60% for the years from 2017 onwards).[452] That people who received the SCM can continue to receive their monthly payments is no answer to the people who were not eligible for the support schemes because they were infected with Hepatitis B or outside the support scheme dates, nor to people who would prefer a lump sum.

Schedule 2 to the 2025 Regulations now contains only a list of rare conditions that qualify for a hepatitis-associated Severe Health Condition award. It is significantly more restrictive than the criteria of the support schemes. Similarly the eligible autoimmune conditions caused by or exacerbated by interferon treatment for Hepatitis C are limited to three, which is more restrictive than the August Scheme Summary and the SCM.[453]

Insofar as adverse mental health/psychological consequences are concerned, the Regulations now require that the individual must have a report from a consultant psychiatrist and evidence that they have been under consultant-led secondary mental health treatment for at least six months, had inpatient admissions or have been sectioned.[454]

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[450] Third Written Statement of James Quinault para 24 WITN7755006

[451] Under EIBSS people could be eligible for the SCM if Hepatitis C or its treatment or complications was making it difficult for them to carry out regular daily activities as a result of mental health problems or as a result of chronic fatigue: chronic fatigue on its own was not sufficient. EIBSS Special Category Mechanism (SCM) application form pp9-12 RLIT0000650. The SIBSS form asked applicants to declare if their life was severely affected by Hepatitis C, moderately affected by Hepatitis C or if Hepatitis C did not have a noticeable day to day impact on their daily life. Severely affected involved a significant impact on the ability to carry out routine daily activities, such as an inability to work or to work full-time due to mental health problems, or an inability to work full-time or carry out day to day activities due to physical health impacts. SIBSS Application to receive Chronic Hepatitis C Payments p2 RLIT0002973. WIBSS asked if the applicant was suffering from mental health issues or post-traumatic stress, related to the infection, affecting the ability to carry out day to day activities. WIBSS Application to receive Advanced Stage 1+ Payments RLIT0002974. The IBPS NI form asked if the applicant was suffering from significant mental health problems, persistent fatigue and/or other health and wellbeing impacts due to Hepatitis C infection as a result of infected blood/blood products which affected their ability to perform daily tasks. IBPS NI Application to receive Hepatitis C Stage 1 (Enhanced) Payments p2 WITN5570034

[452] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 pp50-53 RLIT0002474, Infected Blood Compensation Scheme Summary 31 March 2025 pp46-47 RLIT0002481. For discussion of "*effective treatment*" see *6.3 Hepatitis: date of effective treatment.*

[453] The August Policy Summary which gave the three as examples and the SCM listed the three conditions but also allowed "*Autoimmune disease caused by, or exacerbated by, interferon treatment for hepatitis C*". Infected Blood Compensation Scheme Summary 31 March 2025 p53 RLIT0002481, Infected Blood Compensation Scheme Summary 23 August 2024 p50 RLIT0002945, England Infected Blood Support Scheme (EIBSS) Special Category Mechanism (SCM) application form p8 RLIT0000650

[454] Para 5 of Schedule 2 to the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p91 RLIT0002944

On 29 April 2025 Dr Sarah Helps, the Interim Professional Clinical Lead of the Infected Blood Psychology Service, wrote expressing concerns about the restrictive criteria for the Severe Health Condition award and recommended that "*the supplementary regulations are operationalised to allow for evidence from any qualified doctor, counsellor or mental health professional to support an application for the supplementary award related to severe mental distress.*"[455] It is clear to me that this is essential to meet the justice of the position: the Regulations assume that throughout the country there has been a level of access to psychiatric help which many would struggle to recognise, and it must be remembered that many were deterred from seeking any such help because of the stigma that surrounded Hepatitis as well as HIV.[456] The Inquiry's recommendation on this can be found in the chapter on *Severe psychological harm.*

Commentary

It is profoundly unfair that a promise should be made by the Government and then rowed back from, especially when that promise was made to a group of individuals whose specific pain and suffering had been formally accepted as necessitating additional support from the support schemes. The promise to those in the group was that they would transfer onto the route for a supplementary award without having to evidence their eligibility again: that has been denied, leaving them Hobson's choice of receiving support scheme awards for life. It is an action which has caused significant additional upset to the very people whose suffering has so emphatically been recognised by the Government.[457]

It is deeply unsatisfactory that the result of the careful deliberations of the UK and the other three governments after 2016 when each of them reflected on the shortcomings there

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[455] Statement of concern regarding Infected Blood Compensation Scheme Severe Health Award for people suffering severe psychological distress 29 April 2025 p2 NTHT0000059

[456] It is worth noting here that Mr Justice Burton, who gave judgment in a case which considered in part whether testing for Hepatitis C should have been introduced earlier than it was (*A v National Blood Authority*), said in the course of it that "*Hep C … has also been regularly known as HCV in the medical and blood professions, and the antibody to it, and hence the immunoassay subsequently developed, known as anti-HCV, and indeed Hepatitis B as HBV. This shorthand seems to me to be totally unnecessary and is responsible for a great deal of distress, embarrassment and indeed potentially for economic loss, because of the consequent association with the quite unconnected condition of HIV - the human immunodeficiency virus related to AIDS. The resultant confusion of sufferers themselves, of their relatives and friends, even of doctors and dentists, certainly of employers and insurance companies, has been natural and quite unnecessary. Though it is to be hoped that attitudes towards HIV sufferers change, and that a treatment for HIV is developed and expanded, nevertheless so far as Hepatitis C sufferers are concerned it is important to distinguish between the conditions. So far as concerns the source of infection by Hepatitis C, it can, on the evidence I have heard, almost never be transmitted sexually. Insofar as its consequences are concerned, although it is and can be a serious condition, leading in rare cases to eventual death, many sufferers from Hepatitis C have few or no clinical symptoms, life expectancy is often unaffected and little if any change in life-style results, unlike the present position in relation to HIV sufferers. If this case and the publication of this judgment do any good at all to anyone, the one achievement that can be hoped for is the total and permanent abandonment of the shorthand of HCV, anti-HCV and indeed HBV.*" *A v National Blood Authority* Judgment para 8 PRSE0003333. This judgment was delivered on 26 March 2001, and is contemporaneous recognition of the persistence of stigma at that time that people infected and affected told the Inquiry meant suffering and mental anguish largely stayed behind closed doors.

[457] Not least by the Paymaster General himself. In his opening statement to the Inquiry he said "*I know many people before me will have suffered unimaginably because of this scandal.*" Nick Thomas-Symonds Transcript 7 May 2025 p105 INQY1000283

had been in the Alliance House Organisations – that there was too big a gap between the categories of payment for chronic Hepatitis C infection on the one hand and cirrhosis on the other, which failed to address many of the consequences of the infection and treatment – should be tossed aside in 2025 in the way it was. Though, of course, the Government is entitled to change course if circumstances change, there is no new, unforeseen, development here which justified it. There was little of the careful discussion that had characterised the earlier position. Further, the way the turn around was done lacks both transparency and the involvement of those it most affected.

In designing a scheme that relies on clinical markers to make it relatively quick and easy to operate, requiring only little effort to assess, it can be all too easy to overlook the fact that objective markers may not be the only satisfactory measure. The support schemes worked efficiently in accommodating SCM and its equivalents without needing them. Those schemes provided different levels of payment for different severities, just as the compensation scheme sets out to do. In other areas of law and practice, objective markers to measure pain and disability are often not used. Thus under the Equality Act 2010 compensation is available for those who have been discriminated against on the basis of their disability. A disability is defined for this purpose as having a physical or mental impairment that has a "*substantial*" and "*long-term*" adverse effect on one's ability to do normal daily activities.[458] This necessarily involves the person concerned giving some account of how their physical or mental disability affects them because of what they cannot do. Such an account is not precluded because it may lack a clear "marker" to verify it. Similarly, pain, and the perception of it, is intensely personal. Lawyers practising in personal injury know that different people experience it often to very different degrees even though objectively they may have very similar injuries. The court's award of damages will be heavily influenced by their descriptions of its severity.

My conclusion is (a) that it is not unfair on the public purse to recognise an intermediate category between chronic infection and cirrhosis as fully deserving an award; (b) that given the history a category such as those adopted in each of the four nations should continue to be recognised; and (c) that to leave matters as they are is to perpetuate unfairness both to those currently registered in a support scheme and people infected who are not. This conclusion feeds into the discussion on recommendations at the end of this chapter.

The impacts of treatment and effects of infection additional to effects on the liver

One theme which resonates throughout many of the statements and communications received by the Inquiry, and in the submissions made on behalf of core participants following

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[458] (1) A person (P) has a disability if–

(a) P has a physical or mental impairment, and

(b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.

Section 6 of the Equality Act 2010 p6 RLIT0002969 the hearings on 7-8 May 2025, is whether or not the scheme adequately reflects the impacts of infection with Hepatitis.

Of particular concern are (1) the impacts and ongoing consequences of treatment with interferon (and/or ribavirin) which many endured,[459] and (2) the extra-hepatic consequences of infection.

1. Effects of interferon treatment

Many people infected with Hepatitis C from infected blood and blood products underwent – often repeatedly – treatment with interferon (with or without ribavirin). Until direct-acting antivirals were generally prescribed (their availability increased from around 2011 to 2016) treatment was by interferon alone from 1991 until 1998 when combination therapy (interferon and ribavirin) was approved, followed by pegylated interferon and ribavirin in 2002.[460] As described in the Inquiry Report:

> The vast majority of people suffered severe side effects both physically and psychologically. One of the worst aspects was that despite taking treatment often lasting 48 weeks, more often than not the early treatments failed. Many went through multiple attempts at treatment to try and clear Hepatitis C.[461]

Interferon was approved for the treatment of Hepatitis B in 1992 and pegylated interferon in 2002, though the use of pegylated interferon has been more limited in Hepatitis B than C.[462]

The consequences of these treatments were vividly described to the Inquiry by witness after witness. Some of that evidence is summarised in the Inquiry Report: neutropenia and subsequent infections; severe skin reactions; severe depression; suicidal ideation; severe fatigue; personality change.[463] The following description by one witness summarises the effects experienced by many:

> "*The side effects of my treatment were truly awful, everything was such hard work, I had no energy, shortness of breath, my muscles wasted away, I had absolutely no appetite, I had to start taking antidepressants, I could not sleep, I became very antisocial, very irritable, very weak, I struggled to stay warm even in the summer, I lost weight, I suffered from frequent severe nosebleeds,*

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[459] See for example the Counsel Presentation on Evidence concerning Compensation 29 April 2025 para 28 INQY0000464

[460] The pegylation of interferon increases the concentration of interferon in the blood stream for longer periods. Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p7 EXPG0000001. See also the chapter on *Access to Treatment* Infected Blood Inquiry Report 20 May 2024 Volume 6 pp345-398 INQY0001006

[461] Infected Blood Inquiry Report 20 May 2024 Volume 2 p79 INQY0001002. One striking example is mentioned above at footnote 13.

[462] Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p39 EXPG0000001

[463] Infected Blood Inquiry Report 20 May 2024 Volume 2 pp79-83 INQY0001002

> *nausea, headaches, dizziness, haemorrhoids, very poor concentration (during & after treatment), skin rashes and itchiness, I also suffered from neutropenia during my second course of treatment … these lost years can never be returned to any of us.*"[464]

Witnesses described profound mood shifts and quickness to anger. Some people ended their own lives whilst taking the treatment. The unpredictability of behaviour often had serious social consequences – marriages broke down and children suffered from seeing a parent suddenly become aggressive. It was often impossible to continue in productive work. Very many people continued to suffer from significant physical and psychological symptoms post-treatment.[465] One example of many is:

> "*The consequences of taking these drugs was that I became very violent and short-tempered. I became very argumentative, causing tension with my wife and children. I lost my job and my company, and I was made bankrupt, causing the loss of my house. I lost my will to do anything. To date I still feel generally weak, I have developed allergies and intolerances and I was prescribed to take 125mg Thyroxine because the drugs I was taking destroyed my thyroid. I have managed to learn to live through these health problems in the last 38 years.*"[466]

Another says:

> "*At the age of 17, I received my first treatment with Interferon which caused such adverse effects that it was stopped, after a gruelling six months when I was unable to withstand the horrific side effects. I started experiencing progressive debilitating fatigue, as a result of well over 20 years of long-term hepatitis C infection in combination with a severe bleeding disorder and the effects of aggressive Interferon treatment. I was unable to start my legal career, despite having been given a scholarship. Aged 34, I received Peginterferon Alfa and Ribavirin treatment which caused extremely serious side effects, including life threatening anaemia and multiple episodes of supraventricular tachycardia (SVT). I needed emergency treatment on 18 occasions with Adenosine to stop and restart my heart. This caused immense trauma. The Interferon treatment successfully cleared my HCV but has left me with an autoimmune disease. This prevents my clotting factor from working efficiently, which consequently results in continuous bleeding and low haemoglobin, requiring transfusions of iron every few months. Apparently my particular type of autoimmune disease does not qualify me to claim under the Health Impact supplementary sub-route. I believe the Regulations should allow me to make a claim under this supplementary*

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[464] Infected Blood Inquiry Report 20 May 2024 Volume 2 pp79-80 INQY0001002, Written Statement of Philip Hatton para 20, paras 24-25 WITN0699001

[465] Infected Blood Inquiry Report 20 May 2024 Volume 2 pp85-87 INQY0001002

[466] Mr AE in Written Submissions made on behalf of the core participants represented by Collins Solicitors para 31a SUBS0000092

> *sub-route, as the health consequences of my autoimmune disease are so incredibly severe.*"[467]

The adverse effects of treatment with interferon are detailed in the January 2020 Expert Report to the Infected Blood Inquiry: Hepatitis. These include as common consequences:

(a) infections and infestations including bronchitis, upper respiratory infection, oral candidiasis, herpes simplex, fungal, viral and bacterial infections

(b) blood and lymphatic system disorders such as thrombo-cytopenia, anaemia and lymphadenopathy

(c) endocrine disorders such as hypothyroidism and hyperthyroidism

(d) metabolism and nutrition disorders (with anorexia described as very common)

(e) psychiatric disorders including (as very common) depression, anxiety and insomnia, and (as common) aggression, mood alteration, emotional disorders, nervousness and decreased libido

(f) nervous system disorders, with headache, dizziness and impaired concentration being very common, and common consequences including syncope, migraine, memory impairment, weakness, hypoaesthesia, hyperaesthesia, paraesthesia, tremor, taste disturbance, nightmares and somnolence

(g) eye disorders, including blurred vision, eye pain, eye inflammation and xerophthalmia

(h) ear and labyrinth disorders such as vertigo and earache

(i) cardiac disorders of tachycardia, oedema peripheral and palpitations

(j) vascular disorder of flashing

(k) respiratory, thoracic and mediastinal disorders, with dyspnoea and cough being very common, and common consequences including dyspnoea exertional, epistaxis, nasopharyngitis, sinus congestion, nasal congestion, rhinitis and sore throat

(l) gastrointestinal disorders, with diarrhoea, nausea and abdominal pain being very common, and common effects including vomiting, dyspepsia, dysphagia, mouth ulceration

(m) skin and subcutaneous tissue disorders, including psoriasis, urticaria, eczema, rash, increased sweating, skin disorder, photosensitivity and night sweats

(n) musculoskeletal and connective tissue disorders such as back pain, arthritis, muscle weakness, bone pain, neck pain and muscle cramps

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[467] Ms XX in Written Submissions made on behalf of the core participants represented by Collins Solicitors para 31b SUBS0000092

(o) general disorders, with pyrexia, rigors, pain, asthenia, fatigue and irritability being very common, and chest pain, influenza like illness, malaise, lethargy, hot flushes, thirst, impotence and decreased weight being common.[468]

By contrast, there is only limited discussion about the nature and consequences of interferon in the minutes of the Government's Expert Group's meetings. At the meeting of 12 April 2024, the minutes record, under the heading "*Supplemental awards for the Infected*" that "*It was confirmed that there were some treatments for which individuals would receive a supplemental award due to the difficult nature of receiving this treatment.*"[469] The treatment(s) in question are not identified, and whatever was under consideration at this stage did not make its way into the final scheme, despite it being described as "*confirmed*". Treatment with interferon does not qualify for a supplemental award.

There is a passing reference to interferon in the meeting of the Expert Group on 19 April 2024 but no further reference to interferon in the minutes prior to the publication, on 21 May 2024, of the Government's proposals for the scheme and the Interim Report of the Expert Group. That Interim Report makes no reference to interferon.[470]

In Sir Robert Francis' report of the engagement exercise carried out in June 2024, he records under the heading "*Effects of treatment*" that "*Many contributors to the engagement commented that the banding and staging of injury impact awards did not appear to take sufficient account of the effects of treatment … in particular interferon can in many cases be as bad or worse than the disease itself. In the course of the meetings Sir Jonathan Montgomery undertook to take this point back to the expert group for consideration.*" Sir Robert recommended that if the Expert Group's tariffs had already taken into account the range of effects commonly experienced after treatment, they should explain their reasoning for arriving at the tariffs, and that if the Expert Group concluded it needed to review the tariffs to accommodate this point he recommended that "*either their originally suggested tariffs should be increased to take into account the deleterious effects of treatment, alternatively, a supplementary tariff be introduced for those applicants who can show serious effects over and above the generality of experience taken into account in the core tariff.*"[471]

He noted that over 40% of one representative organisation's survey respondents thought that those treated with interferon should form a separate award category.[472]

There is nonetheless no explicit reference to interferon in the minutes of the Expert Group's meetings prior to the publication, on 16 August 2024, of the Expert Group's Final Report.

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[468] The Report also details very significant adverse effects which are uncommon and some which are rare or very rare. Expert Report to the Infected Blood Inquiry Hepatitis January 2020 pp44-46 EXPG0000001

[469] Minutes of the Infected Blood Inquiry Response Expert Group 12 April 2024 p25 CABO0000925

[470] Minutes of the Infected Blood Inquiry Response Expert Group 19 April 2024 p29 CABO0000925, Infected Blood Inquiry Response Expert Group Interim Report 21 May 2024 RLIT0002478

[471] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p35 RLIT0002466

[472] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p35 RLIT0002466

In that final report the Group stated in its discussion of the injury award for Hepatitis severity Level 2, that:

> "*Comparators have been taken from the National Blood Authority litigation (2001) and also from other personal injury cases involving liver damage, potential lifelong complications, stoma and chronic fatigue. These comparators included compensation for the impact and side effects of treatment with interferon, where the awards ranged in 2001 from £17,000 to £45,000 (current updated values).*"[473]

It is unclear whether the Group reconsidered the position relating to the effects of interferon following the engagement meetings, as anticipated by Sir Robert Francis. The absence of any discussion whatsoever being recorded in the minutes of the Group's meetings would suggest not. However, the minutes are relatively terse: they are not verbatim reports of what was said, and it seems likely that Sir Robert's request to Sir Jonathan Montgomery to take the issue of interferon treatment back to the Expert Group would have then been relayed by him to the Group. If there was indeed discussion, albeit unminuted, then the brief reference in the Group's Report to comparators said to have included compensation for the impact and side effects of treatment with interferon provides no reassurance that the full effects and impact, both physically and psychologically, of treatment with interferon, as set out in the multiple accounts from people infected and affected to the Inquiry, have been fully appreciated and taken into account in the scheme.

In the Expert Group's meetings which followed the publication of its report, the only references to interferon come in the context of limited discussion about the inclusion of psychiatric disorders in the supplementary route. In the minutes of the meeting on 17 October 2024, in the context of a discussion about the Special Category Mechanism, the minutes record that:

> "*The group thought it would be important to ensure that those with HBV had equivalent consideration to those who had HCV, especially where the core route did not capture the impact of SCM and they did not automatically qualify as they had not been eligible for previous support schemes. The group felt that Hepatitis B complications could be characterised via a small list, up until the point treatment was introduced because most complications normalised fairly quickly. Most conditions would likely be lifelong but candidates applying would be rare. The number of people who had interferon who had Hepatitis B was small.*"[474]

On 21 November 2024 the Expert Group discussed the proposed inclusion of psychiatric disorders within the Severe Health Conditions supplemental route. "*It was noted that this award might primarily relate to Interferon treatment, along with a noted higher prevalence of*

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[473] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 p35 RLIT0002474. There is an additional passing reference to interferon when considering Level 4, where the report notes that in a 2001 case that was part of the National Blood Authority litigation an award of £99,000 (current updated value) was made to a claimant "*who had received a liver transplant as well as having received interferon earlier in her treatment.*" Interferon also gets listed in the Annex but the context is setting out the criteria under the national schemes for the SCM and equivalent

[474] Minutes of the Infected Blood Inquiry Response Expert Group 17 October 2024 p57 CABO0000925

Hepatitis C among inpatient mental health patients without substance abuse issues." There is further reference to "*interferon-induced psychosis*" as an example "*that needed further understanding regarding changes to earning and care cost assumptions.*"[475]

Finally on 19 December 2024, as part of the Expert Group's discussion of psychiatric disorders, "*Interferon impacts on secondary psychotic disorders was discussed by the group. It was noted that the wording should change to "any of the disorders caused as a result of interferon*"" and there was "*a consensus that the depressive state should be addressed without linking it to interferon*".[476]

2. Extra-hepatic Manifestations of Hepatitis C infection

> "*A major concern is that the scheme as currently constituted does not sufficiently compensate those who are infected with Hepatitis C, due to the focus of the severity banding on liver damage. The scheme fails to take into account the many non-liver related consequences of Hepatitis C infection, including the impact of treatment, as reflected in the evidence heard by the Inquiry.*"[477]

Samantha May of the Hepatitis C Trust describes:

> "*a complete lack of understanding from the community as to how they've arrived at such low payments for people with Hepatitis C, a devastating disease in itself, not just a liver disease, and for those that have done the older treatments, the treatments for it can also have an incredible physical and mental health impact. Those don't seem to have been included or thought of, perhaps no surprise, because the community wasn't really consulted in the structure of them. They didn't get that input. They didn't get the expertise of organisations like ourselves.*"[478]

Caz Challis refers to:

> "*the muddle of the complicated severity bandings which focus on existing liver damage and ignore all other extra-hepatic consequences and the limited and very selective severe health condition criteria of the supplementary route which has not been informed by the lived experiences of the infected or by the science and was created behind closed doors in secret by the Government's own so-called expert group.*"[479]

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[475] Minutes of the Infected Blood Inquiry Response Expert Group 21 November 2024 p65 CABO0000925

[476] Minutes of the Infected Blood Inquiry Response Expert Group 19 December 2024 p68 CABO0000925

[477] Written Statement of Patrick McGuire of Thompsons Solicitors (Scotland) para 51 WITN7760001. See also the oral evidence of Andrew Evans, reporting the concerns of people about "*The liver-centric assessment of damage in the scale of tariffs for Hepatitis C, ignoring all other impacts of the virus and its treatments.*" Andrew Evans Transcript 7 May 2025 p24 INQY1000283

[478] Samantha May Transcript 7 May 2025 pp45-46 INQY1000283

[479] Carolyn Challis Transcript 7 May 2025 p81 INQY1000283. See also the recommendations of Nicola Leahey (delivered on her behalf by Samantha May): "*I want the extra-hepatic manifestations acknowledged and awarded for*", "*I want the effects of the horrifically physical and psychologically*

The Inquiry heard wide ranging evidence about experiences of many and varied extra hepatic manifestations of Hepatitis C infection (as well as evidence about the effects of treatment with interferon, which is considered above). As the Inquiry Report described:

> The myriad of non-specific symptoms resulting from Hepatitis C were described in numerous written statements. The intermediaries reported: "*People also described the impact of hepatitis C in vivid detail. Chronic, debilitating fatigue was an early symptom, with this lasting for years without diagnosis. Other symptoms were severe aches, gastro-intestinal problems, skin changes and sweating. Cognitive impairment was frequently described as 'brain-fog', a debilitating level of confusion and inability to focus, often combined with anxiety and depression.*"
>
> These symptoms, especially the life-changing impact of debilitating fatigue, have had significant effects on people's lives ...
>
> The impact of Hepatitis C on people's mental health has been profound, particularly in combination with the physical effects of the infection, and the impact of treatment.[480]

There is recognition among hepatologists, supported by the medical literature, that there can be wide ranging extra-hepatic manifestations of Hepatitis C. They were classified in the January 2020 Expert Report to the Infected Blood Inquiry: Hepatitis, and went beyond the significant prevalence of mixed cryoglobulinaemia/cryoglobulinaemic vasculitis and B-cell Non-Hodgkin lymphoma to encompass conditions which had "*higher prevalence in HCV-infected populations compared to controls*". These included Type 2 diabetes mellitus, insulin resistance and metabolic syndrome, glomerulonephritis, renal insufficiency, cognitive impairment, depression, cardiovascular disorders (for example, strokes or ischemic heart disease), Sicca syndrome, arthralgia/myalgia, auto-immune conditions (including rheumatoid arthritis, SLE, thyroiditis), monoclonal gammopathies, porphyria cutanea tarda, lichen planus, Parkinson's Disease, gallstones and irritable bowel syndrome.[481] The Expert

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damaging interferon and ribavirin treatments acknowledged and awarded for." Transcript 7 May 2025 p100 INQY1000283

[480] Infected Blood Inquiry Report 20 May 2024 Volume 2 pp64-73 INQY0001002

[481] The Inquiry Expert Report set out extra hepatic manifestations of Hepatitis C infection according to the strength of the association, as adapted from Cacoub et al:

"***Conditions with significant prevalence, consistent pathogenetic data***

Mixed cryoglobulinemia/cryoglobulinaemic vasculitis

B-cell Non-Hodgkin lymphoma (NHL)

Conditions with higher prevalence in HCV-infected populations compared to controls

Type 2 diabetes mellitus

Insulin resistance and metabolic syndrome

Glomerulonephritis

Renal insufficiency

Cognitive impairment

Depression

Cardiovascular disorders (for example, strokes or ischemic heart disease)

Report to the Inquiry explained that there was evidence that atheroma (fatty deposits on the walls of arteries) could be caused by inflammatory response to Hepatitis C infection, and that there was good evidence that HCV infection was associated with increased incidence of metabolic syndrome, the risk of which persists after cure. "*The complications of metabolic syndrome include hypertension, cerebral haemorrhage, vascular dementia, transient ischaemic attacks (TIA), heart disease, sleep apnoea and polycystic ovarian syndrome (PCOS) ... an increased risk of cancer ...*".[482]

In his report following the June 2024 engagement exercise, Sir Robert Francis recorded that: "*It has been questioned whether the severity bands for HCV took into account EHMs* [Extra hepatic Manifestations]. *I doubt that this is so but clearly the description of the criteria of the bandings should be extended to include the injuries caused by the infection and not be restricted to the liver related symptoms.*" He recorded further concerns that the proposed bandings "*do not reflect the complexity of the condition*" and recommended that "*these concerns should be referred to the expert group for clarification as to whether the factors mentioned by contributors have been taken into account, and if not, what if any modifications are required, and, in particular whether a high level of severity or enhancement is called for.*" He called on the Expert Group to review the proposed bandings in light of these concerns and for the detailed reasoning leading to the proposed range of figures to be published.[483]

Sicca syndrome
Arthralgia/myalgia
Auto-immune conditions, including: rheumatoid arthritis, SLE, thyroiditis
Monoclonal gammopathies
Porphyria cutanea tarda
Lichen planus
Parkinson's Disease
Gall stones Irritable bowel syndrome
Conditions with possible association with HCV
Polyarthritis
Chronic polyradiculoneuropathy
Lung alveolitis
Conditions with anecdotal reports of association
Polymyositis
Dermatomyositis
Polyarteritis nodosa
Psoriasis
Mooren corneal ulcer
Erythema nodosum
Pancreatitis."

Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 pp60-61 EXPG0000001, Cacoub P, Gragnani L, Comarmond C and Zignego AL *Extrahepatic manifestations of chronic hepatitis C virus infection* Digestive and liver disease: official journal of the Italian Society of Gastroenterology and the Italian Association for the Study of the Liver 2014 p2 BNOR0000568

[482] Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 pp61-63 EXPG0000001

[483] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 pp29-30 RLIT0002466

Severity bandings for Hepatitis

In its Final Report published on 16 August 2024 the Expert Group stated that feedback from the engagement meetings:

> "*has prompted us to review the need for an additional banding to reflect the greater impact that some people with HCV have experienced … Some of these aspects of people's experience have already been incorporated into core awards as the advice from the Expert Group is that they affect most people. This is the case for chronic fatigue for all viruses. Others will be less common, but when they arise they will require compensation beyond the core awards.*"[484]

The Group then continued by proposing a supplementary route which would embrace those matters that fell within the Special Category Mechanism and equivalents in the support schemes. As set out in the first part of this chapter that proposal was subsequently abandoned. Nick Thomas-Symonds, in his oral evidence to the Inquiry, suggested 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 ...*"[485]

The submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland), suggest that the Expert Group's position as set out in the Final Report above was 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;*
>
> (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 the 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 … Again, the claim by government that these aspects have been taken into account in the core route 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 at all; and*
>
> (d) *The supplementary route only gives rise to additional claims in respect of financial losses and care needs whereas the additional non-hepatic*

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[484] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 p27 RLIT0002474

[485] Nick Thomas-Symonds Transcript 7 May 2025 pp157-158 INQY1000283

> *manifestations of the infection ought to be recognised as a matter of the equivalent of general damages as well.*"[486]

Paul Desmond of the Hepatitis B Positive Trust says:

> "*what is on offer in respect of compensation for HBV victims does not reflect their lived experience.*"[487]

Commentary

The Inquiry had the benefit, which the Expert Group set up by government did not, of hearing directly from a large number of people about their experiences of infection with Hepatitis (in particular Hepatitis C). The Inquiry asked the clinicians providing independent expert advice to the Inquiry to consider the chronic symptoms, side effects of treatment and health complications described in evidence by people infected and affected and this resulted in the January 2020 Expert Report to the Infected Blood Inquiry: Hepatitis cited above.[488] What people infected with Hepatitis C had to say about their condition often described symptoms and side-effects which went beyond direct damage to the liver itself ("extra-hepatic manifestations"). This evidence, taken overall, was consistent with there being an association between the health effects they reported and their infection with Hepatitis, just as the Inquiry Expert Group had identified. It follows that a scheme of compensation for people infected by Hepatitis C would not adequately compensate them unless it included an allowance for these extra-hepatic manifestations.

As the history of SCM shows, a significant feature in the approach of the compensation scheme to setting severity bands for Hepatitis is whether the extent of the injury is objectively verifiable by use of clinical markers. Point (a) in the submissions from Thompsons Solicitors (Scotland), as set out above, is justified: there is no clear evidence to show how, and if, the likely extent of extra-hepatic manifestations has been taken into account. In the absence of this evidence, I cannot say that it has not been taken into account in setting the Level 2 Hepatitis (Chronic) award – but given (i) the restrictions placed on the Expert Group in its contact with people infected and affected, (ii) its focus on clinical markers of liver deterioration, as such, and (iii) that part of its Final Report of August 2024 where it said that chronic fatigue had been incorporated into core awards, but that other aspects of people's experience "*will be less common, but when they arise they will require compensation beyond the core awards*", I doubt that it has.

Part of a tariff scheme is that it provides a broad level of payment which does justice when viewed across the board, though it will inevitably be the case that some people within a band do not suffer as much as others. On the other side of the coin, some will suffer more

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[486] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.37 SUBS0000084

[487] Written Statement of Paul Desmond para 91 WITN0479044

[488] Infected Blood Inquiry Letter of Instruction to the Clinical Group: Hepatitis 25 September 2019 pp6-7, p8, p10, pp16-23 INQY0000465, Expert Report to the Infected Blood Inquiry: Hepatitis January 2020 p27, pp43-46, pp50-51, pp59-63 EXPG0000001

– but each will receive the same. It follows that in a scheme which in its banding makes allowance for extra-hepatic manifestations, some recipients of an award may not suffer those ill effects, though they were at greater risk of doing so because of their infection, but others will. The banding can neither be set on the basis that most people within the band will be free of these ill-effects, nor that most will suffer worse effects.

It is for government to set the award, and not for me. However, I can identify the appropriate principle (that the compensation must be fair, adequate and proportionate to the range of health effects within a band of the tariff); I have identified weaknesses in the way both Level 2 Hepatitis (Chronic) and the Severe Health Condition awards came to be set; and I can express my individual view that if Level 2 is intended to allow for extra-hepatic manifestations, other than those in a narrow list of conditions justifying a Severe Health Condition award, it is too low.

What counts as Level 3 Hepatitis?

It is at this point that I should deal with an issue of interpretation: as the Regulations are currently drafted, does Level 3 require there to be cirrhosis as most commonly understood by clinicians, or is severe fibrosis sufficient? Has the IBCA been consistent in its approach to this issue?

Schedule 1 to the 2025 Regulations provides the definitions for each level of severity of Hepatitis. The description for Level 1 (Hepatitis C only) is "*Acute infection, being a transient, self-cleared infection*". For Level 2 (Hepatitis B and C), the description is:

> "*Chronic infection characterised by:*
>
> *(a) Hepatitis B – infection with confirmed Hepatitis B surface antigen (HBsAg) positivity for longer than 6 months with detectable Hepatitis B virus DNA on a polymerase chain reaction test, if not on antiviral therapy.*
>
> *(b) Hepatitis C – infection with replicating Hepatitis C virus RNA.*"

For Level 3 (applicable to both Hepatitis B and C), the "*Description of infection severity level*" is:

> "*(1) Cirrhosis, characterised by serious scarring (fibrosis) of the liver caused by long-term liver damage caused by infection*
>
> *(2) Treatment of B-cell non-Hodgkin's lymphoma caused by infection – single round treatment (first line therapy)*
>
> *(3) Type 2 or 3 cryoglobulinemia caused by infection accompanied by membranoproliferative glomerulonephritis.*"

The description for Level 4 (applicable to both Hepatitis B and C) is:

> "*(1) Decompensated cirrhosis caused by infection, characterised by:*
>
> *(a) the presence of hepatic encephalopathy (confusion due to liver damage),*

> *(b) ascites (accumulation of fluid in the abdomen),*
>
> *(c) variceal haemorrhage (bleeding from dilated veins in the gullet or stomach), or*
>
> *(d) a Child-Pugh score greater than 7*
>
> *(2) Treatment of B-cell non-Hodgkin's lymphoma caused by infection – multiple round treatment (second line therapy)*
>
> *(3) Long-term liver damage caused by infection necessitating liver transplantation*
>
> *(4) Presence of liver cancer caused by infection.*"

Level 5 (applicable to Hepatitis B only) is "*Infection resulting in death from acute liver failure within 12 months of infection or within 12 months of reactivation of the infection.*"[489]

Because of the way in which compensation for Hepatitis infection is determined under the Regulations, the decision as to which level is applicable makes a very substantial difference to the amount of compensation payable to an individual. By way of example: the injury (core) award for Level 2 is £60,000; for Level 3 it is £120,000,[490] and the calculation of the financial loss (core) award for infection with Hepatitis B or C (or both but not HIV) for Level 2 is based on an annual amount of £11,863, compared to an annual amount of £23,726 for Level 3.[491]

The definition of Level 3 is a matter of statutory construction.[492] The words chosen matter. So too does the fact that the person who drafted it could have chosen to give a description referring to recognised clinical scores – as was done in relation to Level 4, where the description includes a Child-Pugh score greater than 7 – but did not.

As a matter of construction, the statutory definition provides that – for these purposes – cirrhosis is synonymous with serious scarring of the liver which is synonymous with fibrosis. This does not necessarily mean fibrosis at a minimal level, since if that were so the regulations could simply have said "*fibrosis*", and this might arguably deprive the word "*serious*", which qualifies "*scarring*" of some of its effect.[493]

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[489] Schedule 1 to the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p88 RLIT0002944

[490] Regulation 16(2)(b) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p19 RLIT0002944

[491] Regulation 20(5)(a) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944. These are the levels for the years before "*effective treatment*". See *6.3 Hepatitis: date of effective treatment*. After the year of "*effective treatment*" these sums reduce to £5,931 for Level 2 and £17,794 for Level 3.

[492] The courts ultimately decide what the legislative meaning is, applying well settled rules of construction familiar to judges. I deal with the meaning of the provision here because I have been asked to address it, not because I am asserting some better right to do so because of my past role. It must be recognised that my view cannot be considered determinative. I am not sitting as a court, and it is the court alone that has the right to rule definitively on the correct interpretation.

[493] Like many questions of construction of the meaning of a statutory instrument may never be entirely beyond doubt: the text however sets out a balanced view whilst taking account of these points.

On this construction, Level 3 is met where there is serious scarring or where there is serious fibrosis. The statutory definition does not specify a particular level of fibrosis, so long as it is serious. If a clinical diagnosis of cirrhosis was required, the definition would have said so.

This is not how IBCA has approached deciding whether someone falls within Level 3. Nor, as is set out below, has IBCA taken either a consistent approach, or an approach which has been made public so that individuals and (where represented) their lawyers can know what criteria are being applied.

In his oral evidence to the Inquiry David Foley described a role for a clinical assessor in this regard:

> "*where there are decisions that have to be made that require clinical expertise in particular, for example, thinking about the degree of severity of fibrosis and that would be an example of where a clinical assessor would provide some expert advice that a claims manager simply wouldn't have.*"[494]

He suggested that:

> "*There was a recommendation from the expert panel about what levels would constitute serious scarring, and there are two medical indices, I'm afraid their names escape me at the moment, which also give indications about the scarring. This is where the advice of a clinical assessor is so important. This is not something that a claims manager will be easily able to interpret or decide on, and this is where they would seek the advice of a clinical assessor to say where on those scales is an appropriate place to draw the definition. And I believe there is some -- you know, there are different opinions about where on those scales they should be drawn within the medical profession as well.*"[495]

In a written statement provided after the hearing David Foley has provided more detail about IBCA's approach:

> "*Claim Managers are asked to look for information that confirms cirrhosis or serious scarring or serious fibrosis (as well as any evidence of B-cell non-Hodgkin's lymphoma and Type 2 or 3 cryoglobulinemia caused by infection accompanied by membranoproliferative glomerulonephritis which also provide evidence of Level 3 severity in the Regulations).*
>
> *This evidence could be a medical opinion from a clinician stating that their patient had cirrhosis or had a liver that was cirrhotic, a diagnosis of severe fibrosis or severe scarring, or a Fibroscan score of above, for example, 13, then the Claim Manager is likely to determine this is evidence of Level 3 severity.*

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[494] He added later in his evidence that "*In the role of assessing severity, this is where the claims manager may need the support of, for example, a clinical assessor. And the area that you raised like, for example, the severity of fibrosis, is a good example of one where they would need the assistance of the clinical assessor to make the right decision.*" David Foley Transcript 8 May 2025 p18, p30 INQY1000284

[495] David Foley Transcript 8 May 2025 pp86-87 INQY1000284

> *Where the language is ambiguous with no indication of severity – or where test scores are ambiguous based on clinical advice – then Claim Managers are expected to assemble all the relevant information needed for the Clinical Advisor to be able to provide informed advice. This is because diagnosing cirrhosis at the borderline between the two (our Clinical Advisor indicated 10-12) requires the case details to be considered in the round. This is consistent with the Expert Group's advice to the Cabinet Office that 12.5kPa would be an appropriate cut-off …*
>
> *When a Claim Manager asks for Clinical Advisor advice for a cirrhosis issue, they are briefed and told to provide evidence of the earliest mention of key words, symptoms, tests and treatments relating to Level 2 and Level 3, with context, for the Clinical Advisor to consider … This does not require a diagnosis of cirrhosis to be assessed as Level 3 severity. The Clinical Advisor will consider the case in the round with all the evidence that can be provided in order to inform their advice to the Claim Manager. The Claim Manager will then make a decision taking account of all the information available within the regulatory parameters.*"[496]

He added that IBCA is in the process of reviewing all cases where severity was assessed at Level 2 Hepatitis (Chronic) and there was a query over whether the infection might be cirrhotic rather than chronic, and where Fibroscan scores were above 10, and that IBCA had not discussed this issue with the Cabinet Office.[497]

The Inquiry has been provided with an email exchange between an individual whose compensation was being assessed and a claim manager in which these issues have arisen. In an email of 9 May 2025, the claim manager recorded a discussion with the individual about certain test results and advised that she would "*take this away to our Clinical assessor to discuss whether this would be indicative of Cirrhosis, or IBCA's level 3.*" Later in the email the claim manager recorded the outcome of subsequent discussions with the clinical assessor:

> "*She* [the clinical assessor] *has advised me that the results would not indicate a clear diagnosis for Cirrhosis. However, she did say that it might indicate the start of Cirrhosis. Because the result would be borderline, I have taken this to our policy team to see if there is enough there to use this as a severity change. Policy have just come back to me this morning and advised that I need to go back to the clinical assessor to get a more definitive steer from them on a balance of probabilities in the absence of any further test.*"

The claim manager emailed again on 12 May to say that:

> "*I have spoken again to our clinical assessor today. She has remained consistent in her advice that whilst your results could potentially indicate the beginning of*

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[496] Third Written Statement of David Foley paras 12-15 WITN7757011

[497] Third Written Statement of David Foley paras 16-17 WITN7757011

> *Cirrhosis, she would not say that we could use this as a diagnosis to fit our level 3. I am still having discussions with my senior leaders and policy teams. As it stands our policy team is still advising that we need a diagnosis of Cirrhosis in order to meet the level 3 criteria. However, I do know our board is meeting this week. I am hoping that we will get some clarity from them following the Inquiry hearings.*"[498]

On 29 May the claim manager reverted to say:

> "*I can place you at our level 3 from 2004 on the basis that these results indicate advanced fibrosis.*"[499]

In a further statement David Foley said: "*We do not therefore require a diagnosis of cirrhosis but seek on the basis of the balance of probabilities, to understand whether cirrhosis is likely which could, for example, be record of serious scarring of the liver.*" He explains further that the issue of Level 3 severity "*was briefly discussed with the Cabinet Office when IBCA was developing its operational approach to ask whether the reference to fibrosis had been intended to mean cirrhosis was characterised by fibrosis, or instead to mean cirrhosis as characterised by serious fibrosis. They said the latter which was consistent with the advice that we had received from our Clinical Advisor.*"[500]

Two documents relevant to this issue have been disclosed by IBCA. A "*Key determinations*" document records that evidence of fibrosis (but not "severe" fibrosis or scarring) indicates Level 2; for severity Level 3:

> "*Evidence of symptoms, tests, treatments relating to cirrhosis or other level 3 conditions. For cirrhosis this can be a nuanced assessment based on a range of different test results – so if the description is ambiguous (e.g. "scarring" with no adjective) then take it to the clinical advisor. Include in clinical advisor template mentions of symptoms, treatments, test results and scores (e.g. Fibroscan score – over 11kPa we're treating as cirrhotic unless there's reason to believe it was a spike).*"[501]

Three sources of evidence are noted – Fibroscans and Ishak and Metavir scores from liver biopsies – but the evidence received by the Inquiry shows that many people infected will not have these. For this reason, the IBSS published indices that could be calculated from blood test results.[502] The claim manager is also prompted to look for "*Any mention of alcoholism or needle sharing*". The Inquiry Report recorded, though, that assumptions about alcohol misuse were frequently made, resulting in delays in diagnosis and or treatment, and that

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[498] Emails provided by Jonathan Colam-French May 2025 p5, p2 JCOL0000001

[499] Emails provided by Jonathan Colam-French May 2025 p8 JCOL0000002

[500] Fifth Written Statement of David Foley paras 18-19 WITN7757022

[501] IBCA Key determinations May 2025 p5 IBCA0000002

[502] See for example WIBSS Application to receive Stage II Advanced Hepatitis C Payments pp6-7 WIBS0000072. There are also other indices such as the Fibrosis-4 score calculated from blood tests and age. IBCA Key determinations May 2025 p5 IBCA0000002

the accuracy, or otherwise, of references to alcohol use in medical records has been of particular concern for very many witnesses.[503]

The other document is a Fibroscan chart. It describes four levels of scarring and the possible associated IBCA severity level, with the measure of liver stiffness being kilopascals (kPa). A kPa level of 7-10 is described in the chart as moderate fibrosis and IBCA Level 2; a kPa level of 10-12 as severe fibrosis/cirrhosis and IBCA Level 3; and a kPa of >12 as cirrhosis/advanced fibrosis and IBCA Level 4.[504]

Discussion on the way Level 3 has been understood

There are a number of concerns arising out of the material summarised above about the definition of what constitutes Level 3 severity. First, no information about the discussions taking place has been published so that people infected and their legal representatives might see the basis upon which decisions were being made and contribute to the formulation of IBCA's position. This is despite the fact that a choice between assigning a case to either Level 2 or Level 3 will make a substantial difference to the amounts of compensation awarded. IBCA has revised their internal position shortly after the Inquiry hearings, but this remains unpublished.

Second, it appears variously from David Foley's third statement that a test of "*serious fibrosis*" or "*severe fibrosis*" or "*severe scarring*" may be being used. Not only is this inconsistent with the statutory definition (as addressed above), but "*severe*" is not the same as, and imposes a higher hurdle than, "*serious*"*.*

Third, there has been a lack of consistency in the use of the kPa levels. David Foley's statement refers to a kPa of 13 as sufficient to lead a claim manager to conclude this is Level 3, with 10-12 kPa being described as "*borderline*", such that the evidence needed to be considered "*in the round*". Yet the Fibroscan Chart characterises kPa 10-12 as "*Severe Fibrosis/Cirrhosis*" and as Level 3, and the Key Determinations document indicates that 11 kPa or above should be treated as level 3. Milners Solicitors have told the Inquiry that IBCA has previously sought to apply a kPa score of 12.5 as being required for level 3, has then modified that to 12, and has recently accepted a score of 11.9 as sufficient evidence.

Fourth, the email exchange between the claim manager and individual set out above clearly shows the clinical assessor initially considered that evidence **of cirrhosis** was required (as well as that being the claim manager's understanding of the advice of IBCA's policy team), even though the Regulations say that serious scarring/fibrosis is sufficient.

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[503] Infected Blood Inquiry Report 20 May 2024 Volume 2 p42, Volume 6 pp300-301 INQY0001002, INQY0001006

[504] The chart adds that this is "*a guide only and needs to be used with other evidence where possible to make a severity level decision. FibroScans are not 100% consistent.*" IBCA Fibroscan Chart WITN7757017

Commentary

This chapter has considered three main matters – the Special Category Mechanism, the impacts of treatment and extra-hepatic effects of infection, and the understanding of Level 3 as set out in the scheme. Each makes a compelling case that the impacts of infection with Hepatitis are not being fully recognised (or applied) in the scheme as it stands.

Special Category Mechanism and its equivalents

After reviewing the way in which the SCM in EIBSS and the equivalent categories in the other three nations had been dealt with, I commented above that to leave matters as they are would perpetuate unfairness. It would be unfair both to those currently registered in a support scheme, and those who are unregistered. This is despite both groups being the same in that they were both infected with Hepatitis as a result of transfusion, blood product or tissue transfer. Both would have been entitled to expect, from what the Government had said until early 2025, that if they were in receipt of SCM and equivalents (or would have been had they been eligible for the support schemes) they would be eligible for more compensation than Level 2 Hepatitis (Chronic) on its own would bring. They would be entitled to a Severe Health Condition award as a supplemental award. The result of the about-turn in early 2025 has been an unhappy compromise of denying both groups in different ways, and treating people in the same position in a different manner, unequally: it allows people who were registered with a support scheme to continue being paid support payments at the same level as given to people with cirrhosis, but does not allow people who are unregistered any equivalent; and for people who were registered it denies them the choice of receiving a lump sum from the scheme, calculated on the basis that they will no longer receive support payments.[505]

Interferon treatment

As to interferon treatment, the evidence about it makes a compelling case for its recognition in the compensation scheme. It justifies the view that the effects of treatment with interferon for Hepatitis are amongst the worst consequences of the infections.

If a tariff scheme pays the same sum both to someone whose injury is significantly less severe than that of another, as it does to the one whose injury is significantly more severe, the differences in severity will not be properly reflected. The result will rightly seem unjust to many. Getting the severity levels of award closely calibrated to people's real life experiences was always going to be a challenge. It was always a risk that aspects of the impact of infected blood and blood products might be overlooked, or not given the emphasis they ought to have had. That risk was accentuated by the fact that the Expert Group – on whose reports the Government placed great weight – was precluded by its Terms of Reference from any meaningful interaction with people infected and affected. It was further accentuated

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[505] They theoretically retain choice, but it becomes Hobson's choice in that any award from the scheme will be calculated on the basis they do not qualify for a Severe Health Condition award.

because people infected and affected were not given the opportunity to contribute to the Government's proposals based on the Expert Group's interim report at an earlier formative stage. The consequence was that so many of the insights they could have provided would not have been – and were not – appreciated. Then the risk was increased yet again because consultation was compressed in consequence of the calling of an election and the looming deadline for the making of regulations.

The common theme underlying each factor which accentuated the risk was that what the Second Interim Report had advised was not taken to heart – that decisions should involve those likely to be affected by them, and they should have a "*central influence on* [the scheme's] *decision-making and operation*".[506]

If there had been greater interaction between members of the Expert Group and people infected and affected, at an early stage, and without the pressures of a statutory deadline to meet, it is likely that much greater recognition would have been given to those who had had interferon treatment. The suffering, mood-swings, aggressive tendencies, mental effects, marital consequences, and often inability to work effectively, described above, are such that people who had interferon based treatment deserved – and deserve – to be regarded as in a different category from those who have an infection, but have not received an interferon based treatment. Those who have only had the modern direct-acting antiviral drugs did not suffer these consequences.

The evidence of James Quinault to the Inquiry was that "*the core awards are intended to cover the broad range, both people who had those impacts and those who were lucky enough not to, and it's intended to be set at a level which covers both … then for those even more unlucky to be, you know, severely and permanently -- you know, get a severe, permanent condition because of this, there is the severe health impacts route to pick that up, so that's the intention.*"[507]

He said that there was an assumption for Level 2 Hepatitis (Chronic) that the impact on people's ability to work starts with infection. The intention was "*without asking people to bring forward evidence for how badly they were affected by interferon, to see that they are broadly compensated for it.*"[508]

If that was the intention it has not been achieved. Level 2 Hepatitis (Chronic) is left with too much work to do to represent broad compensation for both chronic infection, involving fatigue, and the after-effects of interferon treatment. The consequences of interferon palpably go far beyond some degree of chronic fatigue.

I conclude that there is in the current scheme a lack of proper recognition of the devastating impacts and effects of interferon treatment. These impacts are detailed in the many written statements which the Inquiry received, the oral evidence which it heard, and the

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[506] Also "*it is important that decisions about those who should receive compensation are not made without them.*" Infected Blood Inquiry Second Interim Report 5 April 2023 p21, p19 INQY0000453

[507] James Quinault Transcript 8 May 2025 pp125-126 INQY1000284

[508] James Quinault Transcript 8 May 2025 p126 INQY1000284

analysis in the January 2020 Expert Report to the Infected Blood Inquiry: Hepatitis. It is not adequately addressed by adjusting the Severe Health Conditions criteria to accommodate it. If "core" means that the conditions most people have suffered can justify a tariff, such that supplemental awards for Severe Health Conditions are for relatively exceptional cases and require further assessment, then having had interferon treatment fits within that core.

Having had interferon treatment should be recognised as being an objective marker for some of the life-changing health consequences suffered by people who were infected with Hepatitis. The conclusion is clear: having had Hepatitis B or C and received interferon treatment justifies a core award above what is currently Level 2 Hepatitis (Chronic), and near or equal to Level 3 for people with Hepatitis B or C.

I have thus far

(a) concluded, in respect of SCM and its equivalents, that it is not unfair on the public purse to recognise an intermediate category between chronic infection and cirrhosis as fully deserving an award; that given the history an intermediate category such as those adopted in each of the four nations should continue to be recognised, notwithstanding a lack of objective clinical markers; and that to leave matters as they are is to perpetuate unfairness both to those currently registered in a support scheme and people infected who are not. (See the Commentary on the section about *The Special Category Mechanism and Equivalents* above.) People who were in receipt of SCM or its national equivalent – which, as it happens, was set at a level equal to that paid by the support schemes to people with cirrhosis – and those who were not registered with a support scheme but would satisfy SCM or its equivalents had losses which went beyond those of people with chronic Hepatitis. SCM and equivalents recognised losses beyond Hepatitis (Chronic) Level 2 that are not limited to the rare conditions qualifying for a hepatitis-associated Severe Health Condition award.

(b) equated the effects of interferon treatment more closely with what is Hepatitis Level 3 than with Hepatitis (Chronic) Level 2.

(c) expressed the view that the Hepatitis (Chronic) Level 2 award is set too low to allow appropriately for extra-hepatic manifestations.

(d) shown how a Level 3 award has been defined by the Regulations, and (sometimes) applied by IBCA. It covers serious fibrosis.

If people who had interferon treatment were to have an award at Level 3 this would do much to address these points.

A recommendation to this effect will do justice without incurring unanticipated cost consequences. In a submission to the Minister for the Cabinet Office of 13 November 2024 the Infected Blood Response Team at the Cabinet Office noted to the Minister that:

> "*In current cost modelling we have treated **all** currently registered SCM individuals on IBSS as receiving Cirrhosis levels of care award and financial loss award. Under the refined health impact group 6 eligibility criteria*[509] *fewer of the currently registered SCM individuals would be eligible for group 6. This is a net reduction in cost compared to our original cost estimate. We estimate that approximately 835 individuals currently registered as SCM on IBSS apply for compensation. If only half are eligible for the Health Impact route, the overall cost of their entire compensation would be approximately £100 million less than our original estimate.*"[510]

The sum involved is thus less than 1% of the sum reserved for payments under the scheme and was included in the original cost estimate.[511]

Recognising interferon treatment in the way suggested would not only be justified in itself, and be consistent with the legislative definition of Level 3, but would go some way towards easing the concerns expressed to the Inquiry that, viewed overall, Hepatitis is under-compensated compared to HIV. Under the scheme, only Level 4 (decompensated cirrhosis) has an award approaching that given to anyone with HIV. There have been calls to award the same, single figure to Hepatitis as awarded to HIV. I do not think this is the right answer to those who have felt that Hepatitis is under-compensated, because it would be a "one size fits all" solution when one size simply does not,[512] and because I consider it reasonable to think in the light of the evidence examined during the course of the Inquiry that tiers are relevant to Hepatitis in a way in which they are not in cases of HIV.

Such a category has a single objective marker – was there interferon treatment or not? – and given the length of courses of treatment involving interferon the giving of it is likely to be recorded in the relevant medical records if they have not been destroyed or become unavailable.[513] It would tend to save some time, too, if it were made a core tariff injury award, and thus in most cases avoid the need for consideration of a supplementary Severe Health Condition award. It should not delay progress this year in rolling out compensation to people who were infected. It may result in additional payments to some people who have already received compensation if they do not have cirrhosis but did receive interferon treatment: but the additional time this might involve is unlikely to be great, and delivers better justice.[514]

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[509] This is a reference to a proposal to remove the symptoms and effects which were regarded as sufficient for SCM and its equivalents from the Hepatitis-associated Severe Health Condition award. This was not published until February 2025, and was not highlighted at the time.

[510] Emphasis in original. Submission on Infected Blood Compensation Scheme: Health Impact Supplementary Sub-Route (Submission B) For Decision 8 November 2024 p8 WITN7755009

[511] £100 million is 0.847% of £11.8 billion. The sum was within the estimated cost before the Government rowed back on their acceptance of an SCM type category amongst those entitled to a severe health condition award.

[512] The Inquiry rejected a "one size fits all" approach in the Second Interim Report. Infected Blood Inquiry Second Interim Report 5 April 2023 p17 INQY0000453

[513] And in the event of medical records not being available, interferon treatment is likely to have had such an impact as to be readily recalled by those who underwent or witnessed it.

[514] People who suffered extra-hepatic manifestations of Hepatitis which go beyond Level 2 and predated interferon treatment, and who did not progress either to interferon treatment or to cirrhosis, may require

The Minister has available a simple answer to the essence of the points made in this chapter about the way the SCM and its equivalents, having interferon, and suffering extra-hepatic manifestations have been treated, and the proper scope of "cirrhosis" as defined in the Regulations. It is to recognise that having had interferon treatment justifies a core award, I would suggest at Level 3, on the pragmatic basis that the appropriate consequences in terms of financial and care core awards then follow. This requires less by way of amendment of the Regulations than introducing a Level 2B and making consequent provision throughout the Regulations for this, though the choice – 3 or 2B – is for his judgment.

I recognise that there may be some people who have experienced severe disability which either did or would have entitled them to an SCM or equivalent award who did not undergo treatment with interferon.[515] This leads to my second recommendation below.

I recommend that: People infected with Hepatitis B or C who have received a course of treatment with or based on interferon should be recognised as entitled to core awards at Level 3.

I also recommend that: The Government reconsider whether to maintain its rejection in February 2025 of the recommendations of Sir Robert Francis KC and advice from the Infected Blood Inquiry Response Expert Group of August 2024, which was expressly accepted at the time by the Government, to introduce (as one of six health impact groups which would justify a severe health condition award) the following for people infected with Hepatitis B and Hepatitis C:

> ***"Other Hepatitis C associated extra hepatic disorders resulting in long-term severe disability. This includes those currently assessed as the following category on IBSS:***
>
> ***- Hepatitis Special Category Mechanism (EIBSS)***
>
> ***- 'Severely Affected' Hepatitis C (SIBSS)***
>
> ***- Hepatitis C Stage 1 Plus (WIBSS)***
>
> ***- Hepatitis C Stage 1 Enhanced Payments (NIIBSS)"***

The consequence of the first of these recommendations is that people infected with Hepatitis who were treated with interferon would become eligible for Level 3. This will be the majority of people who are in receipt of the SCM and equivalents, or would have qualified for it had they been eligible for the support schemes.

The second of these recommendations relates to people infected with Hepatitis at severity Levels 2, 3 or 4 who fit the criteria described in the Expert Group's Final Report, which echo the criteria used to award SCM and equivalents in the national support schemes and include autoimmune disease due to or worsened by interferon treatment beyond the three conditions

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further consideration. See the chapter on *Recommendations*.

[515] Or whose auto-immune disease due to or worsened by interferon treatment is not recognised by the compensation scheme.

now recognised. If on reconsideration the Minister accepts that the recommendation of Sir Robert Francis that the advice of the Expert Group in August 2024 should be followed, they would be classed as suffering from a "*Hepatitis-associated condition resulting in long-term severe disability*".[516] They could apply for a Severe Health Condition award, which would be made in respect of the period from the date they experienced that long-term severe disability, and entitle them to supplementary care and financial awards calculated from the onset of that disability – in line with the existing awards made for this Severe Health Condition.[517] The implementation of this should involve meaningful consultation with people infected. Anyone in receipt of SCM who did not wish to make an application for a supplementary Severe Health Condition award would in any event retain the option they currently have to continue support payments for life.

To make one recommendation without the other would have been to fail to recognise the full extent of the losses associated both with the consequences of infection with Hepatitis B or C (or both) beyond those that affect only the liver directly, and with the consequences of treatment with or based on interferon. The first involves a single objective marker. The second does not, but the experience of the support schemes shows that it is possible to recognise long-term severe disability without significant difficulty in the way they did, and it would be fair to do so.[518]

Recognising the impact of interferon would on its own significantly increase the fairness of the compensation for infection with Hepatitis without the delay of wholescale change. If the Minister reconsiders the decision in respect of SCM and equivalents to restore what it was said to be in August 2024 that too would increase fairness, and would not involve significant delay. Taken together they would achieve greater justice.

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[516] The phrase used in para 7 of Schedule 2 to the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p92 RLIT0002944

[517] In accord with Regulations 30, 31(7) (care) and 32(6) and (7) (financial loss).

[518] The rationale that it is neither appropriate nor proportionate to require applicants to make personal life impact statements, necessary to satisfy the criteria, misses the point that no-one is **required** to make an application for a supplementary Severe Health Condition award. Their autonomy should be respected. They may choose to do so (or not to do so), knowing that it is to ask for something which necessarily depends on a personal account. Their choice should not be denied by making it the reason why such an award should not be made.

6 Specific concerns

6.1 Introduction

The sections in this chapter look at issues which arise out of the way in which specific provisions have been drafted or interpreted, which have emerged in the light of experience and developing understanding of the effects of the Regulations in practice.

Some require a concentration on the detail. Describing some of them is describing technicalities. One of the undeniable features of the scheme as set out in the Regulations is its complexity.

Explaining an intricate process in words may not be as quickly impactful as telling a story – the effects, for instance, of an equation used in the Regulations does not resonate with many readers' personal experiences as much as, for instance, an account of how children were prescribed products which risked their health and their lives when there were safer treatments available which their parents were not told about.

However, the effect of those technicalities is not at all technical: it is all too real to those to whom they make a difference.

The fact that they arise out of "technicalities" of the scheme should not obscure the four questions which usually arise in the case of each:

(1) Does it disadvantage some people compared to others?

(2) If yes, does it do so fairly?

(3) If no, is the provision as it stands necessary?

(4) If yes, is there a simple modification which makes it fairer?

6.2 Severe psychological harm

Entitlement to a supplemental Severe Health Condition award arises only if a person has one of the conditions described in Schedule 2 to the 2025 Regulations.[519] Schedule 2 recognises adverse mental health/psychological consequences only where a person has, or had, "*a severe psychiatric condition*".

To come within the definition of a severe psychiatric condition, paragraph 5(1) of Schedule 2 requires the following to be proved:

> *"(b) a consultant psychiatrist has–*

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[519] See Regulation 28(1) and Schedule 2 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp27-28, pp88-93 RLIT0002944

> *(iii) diagnosed P with a condition described in sub-paragraph (2),*[520] *and*
>
> *(iv) confirmed that P's infection or any consequent interferon treatment is the cause, or a major cause, of the condition or of its course, and*
>
> *(e) as a result of the condition, P has received–*
>
> *(i) consultant-led secondary mental health treatment for a period of at least 6 months, or*
>
> *(ii) assessment or treatment as an inpatient (compulsorily or otherwise).*"[521]

A severe psychiatric condition award can be for one of two levels of care, domestic support or low care (£5,460 or £23,42.72 per annum). For the higher award, a "*Social services needs assessment confirming requirement for long term personal and domestic care as defined by scheme in the 'low care' band*" is required.[522]

In practice, few individuals who suffered serious mental health difficulties in consequence of infection with HIV or Hepatitis will be able to satisfy these restrictive criteria.

On 29 April 2025 Dr Sarah Helps, the Interim Professional Clinical Lead of the Infected Blood Psychology Service ("IBPS"), wrote expressing the concerns of the IBPS about the restrictive criteria for the Severe Health Condition award:

> "*The tariff-based core route is not designed to make provision for different levels of psychological distress. IBPS is therefore increasingly concerned that the supplementary route of the scheme does not adequately make provision for the full range of severe psychological distress experienced by both infected and affected people.*
>
> *IBPS is concerned about the way in which the severe health conditions award of the supplementary route has been drafted in relation to mental distress. The severe health condition award indicates that this route can only be claimed if a person received psychiatric care lasting over six months which may have involved an in-patient stay.*
>
> *However, IBPS believe that access to services would have been significantly impacted by issues such as a lack of understanding of the psychological and psychiatric sequelae of infected blood, stigma of accessing mental health*

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[520] These conditions are depressive disorders, bipolar disorders, generalised anxiety or panic disorders, post-traumatic stress disorders, adjustment disorders, or secondary psychotic disorders caused by HIV brain disease, HIV-related central nervous system opportunistic infection or neoplasia. See para 5(2) of Schedule 2 to the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p91 RLIT0002944

[521] Paragraph 5(1) of Schedule 2 to the Infected Blood Compensation Scheme Regulations 2025 p91 RLIT0002944

[522] Infected Blood Compensation Scheme Summary 31 March 2025 p51, p47 RLIT0002481, Regulation 29(5) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p28 RLIT0002944

> *services and indeed psychiatric service thresholds, leaving thousands of people without access to much needed care.*
>
> *Furthermore, over past decades, beneficiaries are much more likely to have been assessed and treated by psychologists and counsellors in specialist services funded by the Infected Blood Support services, rather than by core mental health services. It is these professionals who would have assessed and treated the severe psychological harm experienced by beneficiaries.*
>
> *It is unhelpful and unfair to expect a consultant psychiatrist to have provided a formal psychiatric diagnosis together with in-patient treatment, in order for supplementary compensation to be considered.*"

IBPS recommends that "*the severe health category is reworded to accept both a diagnosis made by a psychiatric professional* ***and*** *a formulation-based opinion of all qualified psychological and counselling professionals as supporting evidence of severe harm within a supplementary compensation claim.*"[523]

The Scottish Infected Blood Forum point out that the scheme

> "*does not take into account the attitudes and perceptions which prevailed in UK society throughout the 1970s, 1980s, 1990s, and early 2000s towards many aspects of the infected blood disaster, one of which is mental health … most people were infected during a time when mental health was still poorly understood and came with a range of stigma and negative connotations … Although some of the attitudes towards mental health began to change in the late 1980s and into the 1990s, people who had mental health issues related to infected blood, either as someone infected or affected, were already feeling ostracised and abandoned by the NHS, by the state, and sadly in too many cases, by their communities, and even parts of their own families.*"

They urge that the scheme "*must be opened up to change the too restrictive criteria … This includes making it simpler to demonstrate mental health impacts.*"[524]

It is not clear why the criteria for qualifying under the supplemental route on the basis of a severe psychiatric disorder were drafted so restrictively. As noted earlier in this Additional Report, the membership of the Expert Group did not include any psychiatric/psychological/

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[523] Emphasis in original. Statement of concern regarding Infected Blood Compensation Scheme Severe Health Award for people suffering severe psychological distress 29 April 2025 NTHT0000059

[524] They add: "*Why is a GP's clinical and professional opinion, or clear written evidence, that a patient is suffering from depression, anxiety, PTSD or any other number of mental health issues, not being accepted as evidence?*" Scottish Infected Blood Forum Infected Blood Compensation Reset – A Parallel Process May 2025 pp18-20 SUBS0000101. Similar observations are made in the Written Submissions on behalf of the core participants represented by Leigh Day: "*Requiring psychiatric evidence from a psychiatrist and care reports from social services, rather than accepting reports from psychotherapists or GPs, imposes an unnecessary burden on applicants. Indeed, the Inquiry has heard that interactions with such professionals is not part of the usual patient journey." Written Submissions on behalf of the core participants represented by Leigh Day para 48 SUBS0*000088. The written submissions on behalf of the core participants represented by Saunders Law echo this. Written Submissions on behalf of the core participants represented by Saunders Law paras 11-12 SUBS0000089

psychosocial expertise, nor did the Expert Group speak directly to, nor hear from, any people infected or affected.[525] The minutes of the Expert Group's meeting on 10 July 2024 record that "*There was a discussion on psychiatric disorders and the Expert Group agreed that there was a need for significant evidence for classification.*"[526] Returning to this issue the following day, the Expert Group recorded:

> "*there would need to be examples for the thresholds for severe psychiatric disorders. Inpatient care is a very high threshold and there are potential problems. Three months treatment is standard for mild or moderate psychological harm but the counterproposal would be to increase it to six months for consistency. The group asked whether the issue of prognosis would need to be considered.*"

It was minuted that the Chair would seek advice from Professor Sir Simon Wessely on whether the use of ICD categories "*might be a way forward for the category of severe psychiatric disorders.*"[527] The Expert Group returned to the issue of severe psychiatric disorders at its meeting on 31 October 2024 and the minutes record:

> "*They noted that it would be hard to separate clinical manifestations of different disorders. They agreed that there would need to be a significant change after infection to ensure there was a reasonable confidence that it was due to the impact of the infection. It was noted that a certain level of poor mental health was already considered under the core award.*
>
> *The group discussed how to change financial loss and care as a result of those diagnoses. One proposal suggested by the group was that a consultant psychiatrist reviewed the person and there was regular or inpatient treatment and that this could be an appropriate threshold.*"[528]

By the time of the meeting of the Expert Group on 21 November 2024 a "*conversation*" had taken place between the Cabinet Office and the Department of Health and Social Care, "*which resulted in further refinement of the condition list. A proposal was shared with the group, focusing on which conditions might increase the likelihood of someone requiring psychiatric care due to infected blood.*" The "*list*" would be discussed further with the DHSC.[529]

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[525] See 2 Design of the compensation scheme.

[526] In the course of a discussion on "*Severe Neurological Disorders*" in the same meeting, the Group appeared to return to the issue of psychiatric disorders: "*It was noted that severe psychiatric conditions should warrant 100% financial loss; however, significant evidence of diagnosis through psychiatric assessment would be required. Evidence indicating the inability to work must come from a psychiatric evaluation, rather than primary care.*" Minutes of the Infected Blood Inquiry Response Expert Group 10 July 2024 p40-41 CABO0000925

[527] Professor Sir Simon Wessely is a Past President of the Royal College of Psychiatrists and the Royal Society of Medicine. ICD stands for the International Classification of Diseases published by the World Health Organisation. Minutes of the Infected Blood Inquiry Response Expert Group 11 July 2024 p43 CABO0000925.

[528] Minutes of the Infected Blood Inquiry Response Expert Group 31 October 2024 p58 CABO0000925

[529] Minutes of the Infected Blood Inquiry Response Expert Group 21 November 2024 p65 CABO0000925

Commentary

The circumstances in which infected blood caused the diseases it did were unique. It was telling that one of the explanations that some families adopted to explain why one of their number was so obviously in ill health, struggling, unable to work, showing signs of mental disturbance and changes of personality, was that they had cancer. They did so knowing that a diagnosis of cancer would attract sympathy, whereas admitting to HIV would invite ostracism and worse, and aware that Hepatitis B or C was regarded as dirty, linked with alcoholism, illicit drugs and prostitution in the public mind.

It was features like these which made it so difficult for people even to tell family and friends the truth, and it is why some people who had witnessed the stigma that infections gave rise to had not told members of their close family by the time they gave a statement and even oral evidence to the Inquiry. Some would not go as far as making a statement anonymously, but gave their accounts to trained intermediaries who could relay the substance of what they had to say without anything that might identify the individual – just in case.[530]

That feature is one of two that make it unrealistic – and unfair – to require that a person who was infected should have to show either in-patient treatment or six months consultant-led secondary care as a necessary step toward being recognised as entitled to a Severe Health Condition award on the basis of their mental state. It would have involved revealing, to an unknown clinician, what that person dared not reveal, especially if there was any chance that it might leak out. Access to a consultant psychiatrist would most probably involve referral from others, who would also have to be put in the know.

The second feature is that consultant psychiatric services were not the norm across every part of the country, and across most of the relevant periods. It would be wrong to set a requirement for compensation that such services be accessed when it was not a practical proposition that they could be.

This was neatly summed up by the Infected Blood Psychology Service in the words I have already quoted above, but which deserve repetition:

> "*IBPS believe that access to services would have been significantly impacted by issues such as a lack of understanding of the psychological and psychiatric sequelae of infected blood, stigma of accessing mental health services and indeed psychiatric service thresholds, leaving thousands of people without access to much needed care.*"

It is difficult to believe that the hurdle of proving severe psychological harm would intentionally have been placed at a level that would make it close to impossible for people to be able to demonstrate it. Yet, though almost certainly unintentionally, that is the effect of the way in which the Regulations have been drafted.

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[530] Intermediaries Report 2019 15 January 2020 WITN4000001, Intermediaries Report Supplementary 2 June 2023 WITN4000002

I recommend that: The approach of the Infected Blood Psychology Service is adopted so that both a diagnosis made by a psychiatric professional and a formulation-based opinion of all qualified psychological and counselling professionals are accepted as sufficient evidence of severe psychological harm and that such evidence should qualify a person for a supplementary Severe Health Condition award without the additional need to demonstrate a period of consultant-led secondary mental health treatment or assessment/treatment as an inpatient.

6.3 Hepatitis: date of effective treatment

Regulation 20(6)(c) of the 2025 Regulations introduces the concept of "*the year of effective treatment*". This is determined by the Regulations to be 2008 where a person is infected with Hepatitis B and 2016 where a person is infected with Hepatitis C.[531]

The effect of "*the year of effective treatment*" is to reduce significantly the annual amount of compensation payable from 2009 (for Hepatitis B) and 2017 (for Hepatitis C) as part of the financial loss core award. The annual amount payable reduces in the case of Level 2 severity from £11,863 to £5,931 and in the case of Level 3 severity from £23,726 to £17,794.[532]

The Final Report of the Expert Group states that:

> "*Hepatitis C: Effective curative treatment for HCV was widely available from 2016 onwards - these directly acting antiviral agents (DAAs) had minimal side effects (by enlarge* [sic]*) and were very efficacious even enabling a subset of patients with decompensated cirrhosis to improve back to compensated disease.*
>
> *Hepatitis B: Effective treatment for HBV was widely introduced circa 2008 with the wider availability of Entecavir and Tenofovir. Prior to that weaker antivirals were widely used (e.g. Lamivudine) from circa 1998 but were associated with the development of resistance making treatments ineffective.*"

The Expert Group advised that these adjustments should not be applied from the age of 55, "*given how difficult it is to re-enter the workforce after a period of absence. This point was made strongly in the engagement meetings.*"[533]

The minutes of the meetings of the Expert Group disclose relatively limited discussion of this issue. At the meeting of 7 March 2024, it "*was noted that those with Hepatitis C will have been provided curative treatment, halting the progression of their disease. A small proportion (approximately 2%) of those who have received curative treatment may go on*

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[531] Regulation 20(6)(c) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944

[532] Regulation 20(5)(b) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944. In Level 2 cases, the reduction is to half the pre-2009/2017 figures; in Level 3 cases it is to three-quarters. The reduction is in each case by a sum of the same amount. The difference in percentages comes about because that sum equals half the sum given to Level 2 pre-2009/17, and one quarter of the Level 3 previous annual loss.

[533] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 p51 RLIT0002474

to develop liver cancer."[534] On 18 April 2024 the Group "*discussed varying financial loss dependent upon infection severity and availability of treatment. The group felt that this might not be proportionate for those with HIV. The group agreed that for HCV more discussion was required.*"[535] There was then a further discussion on 19 April:

> "*For HCV the group discussed whether there were clear transition points which resulted in significantly reduced impact on someone's ability to work. For those that were diagnosed prior to 2014 meant exposure to treatments like interferon. When new DAA drugs were first introduced they were prioritised by the level of severity but they were not widely available on the NHS for all patients who wanted them until 2017 … Anyone infected post-2015 would have access to curative treatment within 3 years and would have significantly reduced impact. The group concluded there should be two bandings. One was pre-introduction of DAA (effective treatment) and one was post-effective treatment. Having a clear reduction post-treatment would also future proof the scheme given there was a small ongoing risk of HCV infection.*"

More generally the Group observed that "*For HCV the assumption was that some work would have been possible and therefore financial loss would be applied at different levels across different years.*"[536]

There is thus little in either the Expert Group's Final Report, or in the minutes of their meetings, which provides an evidential basis for the assumption which presumably underpins the use of the "*date of effective treatment*", namely an assumption about people's ability to work post-treatment.[537]

The unpublished Engagement Explainer provided to campaigners during Sir Robert Francis' consultation in June 2024 stated:

> "*The following assumptions have been made in calculating financial loss for living infected persons:*
>
> - *For Hepatitis C - it is assumed that the introduction of effective treatments in 2016 improved an infected person's ability to work. See Annex C for further detail.*
> - *For Hepatitis B - it is assumed that the introduction of effective treatments in 2008 improved an infected person's ability to work. See Annex C for further detail.*"

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[534] Minutes of the Infected Blood Inquiry Response Expert Group 7 March 2024 p15 CABO0000925

[535] Minutes of the Infected Blood Inquiry Response Expert Group 18 April 2024 p28 CABO0000925

[536] Minutes of the Infected Blood Inquiry Response Expert Group 19 April 2024 p29 CABO0000925

[537] The Expert Report to the Infected Blood Inquiry: Hepatitis noted "*To answer the question about post treatment complications or effects one must also consider any treatment side effects that persist. The answer is very dependent on what treatment has been used; the major distinction being interferon containing therapy and interferon-free therapy. It is important to note that for much of this area there is an absence of high quality evidence, rather than clear evidence of an absence of effect.*" Expert Report to the Infected Blood Inquiry Hepatitis January 2000 p59 EXPG0000001

Annex C provided illustrative financial loss award calculations, though with dates that did not illustrate the step-down in payments.[538]

Following his consultation, Sir Robert Francis advised that more work was needed on the Financial Loss awards:

> "*The proposal is clearly a start in identifying such a tariff, but more work is needed. The assumptions underlying the proposed structure are that for a possibly substantial period an infected person will have a substantial earning potential … I accept these assumptions are, as stated, based on the clinical advice of the advisory group, but I suggest that their reasoning and the evidence on which it is based should be shared to enable the community to understand their formulation.*
>
> …
>
> *The proposal makes assumptions about the positive impact of treatments introduced in 2016. Many contributors have raised concerns about this, asserting that the beneficial effect of treatment on the disease were not necessarily accompanied by a return of the ability to obtain work – either because relevant symptoms continued, or because of the diminished prospects in obtaining employment after a lengthy absence due to incapacity. Sir Jonathan agreed to consult his group about this point. I understand that the group's advice is that most infected persons were able to return to work after modern treatments.*[539]
>
> [The word "modern" should be noted – in context it refers to the direct-acting antiviral drugs introduced progressively from 2008 (Hepatitis B) and 2015/16 (Hepatitis C).]
>
> *However, on reconsideration, it was agreed that those suffering from chronic fatigue, or were aged 55 or over, found getting employment significantly more difficult. For those latter groups, they recommend that the potential for returning to work should be disregarded.*
>
> *Recommendation*
>
> *42. On the basis of the evidence, I agree that the proposal should be amended accordingly, to allow for a disregard of the assumption, subject to the provision of some evidence of ongoing chronic fatigue, if that is the ground relied on. The implication of the advice is that not all other infected persons will have been able to return to work. Accordingly, I recommend that on production of some evidence*

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[538] Infected Blood Compensation Scheme - Engagement Explainer June 2024 pp15-16, pp35-38 WITN7752004

[539] As discussed in *2 Design of the Compensation Scheme*, the Terms of Reference of the Expert Group meant they were unable to consult with people infected, a significant proportion of whom had the debilitating earlier treatments with their ongoing effects before modern treatment.

> *to support such a claim, such as a medical certificate, a supplementary claim should be allowed.*"[540]

The Final Report of the Expert Group of 16 August 2024 extended this as follows:

> "*Supplemental route: Whilst the categories above are designed to enable rapid processing of individual claims, it is recognised that there will be some individuals whose ability to work is fully hampered due to the fatigue they experienced. There is also clear evidence that some individuals experienced HCV or HBV-associated stigma and discrimination in the workplace. In such cases, individuals will be able to apply* [sic] *higher levels of financial award via the supplementary track to bring their financial loss compensation inline* [sic] *with their actual financial loss.*"[541]

This was a reasonable extension of Sir Robert's recommendation.

The Government's update, published the same day, reported that the Government had accepted 69 of Sir Robert's 74 recommendations. This was not one of the rejected recommendations and the short update stated:

> "*In addition to the core route, a 'supplementary route' will also be available to provide additional awards for applicants whose losses are not adequately covered by the core route.*"[542]

On 23 August 2024 (the day the 2024 Regulations were made and came into force) the Government published a policy paper providing more detail about the scheme. Under the heading "*Evidence-led supplementary sub-route*", this paper stated:

> "*Applicants will need to provide evidence of their financial loss … This sub-route will enable applicants to provide evidence of their actual losses beyond the awards in the Core Route … Further detail will be made available in due course.*"[543]

The Expert Group discussed the supplementary Financial Loss award that autumn but the minutes do not record specific discussion of Sir Robert's recommendation which had been accepted and expanded by the Expert Group in their Final Report.[544]

The first indication that the recommendation might not be implemented, as with the Special Category Mechanism issue described in the chapter on *Hepatitis*, came in an unpublished factsheet shared by the Cabinet Office with campaigners in January 2025. It stated:

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[540] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 pp58-60 RLIT0002466

[541] Infected Blood Inquiry Response Expert Group Final Report 16 August 2024 p53 RLIT0002474

[542] Government Update on the Infected Blood Compensation Scheme 16 August 2024 p6 WITN7760006

[543] Infected Blood Compensation Scheme Summary 23 August 2024 p29 RLIT0002945

[544] Minutes of the Infected Blood Inquiry Response Expert Group 24 September 2024, 7 November 2024 pp51-52, pp59-62 CABO0000925

> "*An additional Financial Loss award can be awarded to infected people in two different circumstances. The first is for those who suffered from a specified rare severe health condition as a result of their infection … The second is where an infected person can provide evidence that they would have earned more than is assumed by the core awards. This is* ***likely to be for*** *people who were in particularly high paying careers before they had to reduce work or stop altogether.*"[545]

I have highlighted the words "*likely to be for*" because they do not say "*only for*". This left open the group which the Expert Group, and Sir Robert had in mind – those people who had not yet reached 55 by 2009 (for Hepatitis B) or 2017 (for Hepatitis C) but who found that the side effects of treatment and/or the condition in which the treatment, if successful, had left them, or the consequences of stigma and discrimination, had made it difficult or impossible to return to work as before. However, though the words do not exclude this group, they do not specifically mention it.

On 12 February 2025, when the 2025 Regulations were laid in draft, an Addendum Report from the Expert Group was published. This explained that one of the three issues the Expert Group had been invited by the Government to provide further detailed advice on was:

> "*Exceptional Loss awards to substitute actual amounts for financial loss awards or care awards where it is shown that the loss or cost significantly exceeds the assumption that underpin the core awards.*"

However, the Addendum Report went on to state:

> "*The aim of the Exceptional Loss supplementary route is to address the position of beneficiaries whose earning potential is greater than the core award of UK median earnings plus 5%.*"[546]

The updated Scheme Summary similarly stated:

> "***Supplementary route: Exceptional Loss awards (to recognise higher earnings and/or paid-for care costs)***
>
> *Depending on their personal circumstances, we expect that there will be a small number of infected people who suffered greater financial loss or care costs as a result of their infection than the tariff-based compensation available under the core route. Infected people who can provide evidence of greater financial loss and/or care costs as a result of their infection will be able to apply for the Exceptional Loss awards through the Supplementary route.*
>
> *The people eligible for these awards will be:*

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[545] Draft Infected Blood Compensation Scheme Regulations 2025 Factsheet January 2025 pp6-7 WITN6392300

[546] Infected Blood Inquiry Response Expert Group Addendum to Final Report 12 February 2025 p5, p18 WITN7762015. This is discussed in *6.8 Exceptional reduced earnings*.

- *Infected people who were particularly high earners and suffered a reduced ability to earn because of their infection …*"[547]

By way of comment, what is meant to be compensated here is the high earner, who can demonstrate from their past history that their earnings (before they were infected) were greater than the salary levels assumed by the scheme.[548] The proposed consequence is to allow the scheme to give them more, because the sums provided by the core route (in their exceptional case) were not enough. By contrast, what had been under discussion for those who could not get back to work was not people whose salaries were particularly high, but another group – people in whose case it was assumed that they had recovered an ability to earn a substantial proportion more than they had for some years, so that the scheme provided that they should receive less by way of compensation, but for whom the assumption was unjustified in their particular case. The core route was drafted on the assumption that as a result of successful treatment with modern drugs they would only suffer half[549] or three-quarters[550] of the annual loss of earnings which the core route covered in its tariff award up to that point, such that the annual financial loss for a person with an infection of their severity level would be as little as half what it would have been for the years before 2009 (Hepatitis B) or 2017 (Hepatitis C) in the case of a person with Level 2 severity, and three-quarters in the case of a person with Level 3 severity of infection.

In neither the Addendum Report nor the Scheme Summary was there acknowledgement of Sir Robert's recommendation regarding people who had found difficulty in returning to work because of fatigue persisting after treatment, and the Expert Group's extension of it by recognising that some individuals experienced HCV or HBV-associated stigma and discrimination in the workplace. There was no express recognition that the after-effects of earlier treatments involving interferon might effectively prevent a return to work to the extent assumed in the 50%-25% reduction applied to a core route calculation.

The Regulations as Made

A person whose core award is reduced to allow for the effects of successful treatment has no route to show that in their case there should be no reduction. This is because the Regulations not only do not allow for it, but appear effectively to exclude it.

Regulation 35 is clear about who is eligible for an "*exceptional loss award*". It provides that such an award will be made:

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[547] Infected Blood Compensation Scheme Summary 31 March 2025 p29 RLIT0002481.

[548] "*To be eligible for an additional Exceptional Loss award for financial loss, applicants need to have had had [sic] annual earnings in excess of the following amounts before their reduction in earnings due to the infection: i. Applicants with Hepatitis B or C will need to have earned at least the 60th percentile UK salary (equivalent to gross salary of over £44,204 in 2023 value) …*" Infected Blood Compensation Scheme Summary 31 March 2025 p30 RLIT0002481

[549] In the case of Level 2 severity.

[550] In the case of Level 3 severity.

> "*(1) … where–*
>
> *(a)* *P* [an eligible infected person] *has–*
>
> *(i)* *suffered exceptional reduced PAYE earnings,*
>
> *(ii)* *suffered exceptional reduced self-employment earnings …*"

It goes on to provide by (2) that:

> "*An exceptional loss award may* ***only***[551] *include–*
>
> *(a)* *one of the following …*
>
> *(i)* *an amount by way of a financial loss (PAYE earnings) award, or*
>
> *(ii)* *an amount by way of a financial loss (self-employment earnings) award*"[552]

To understand what counts as "*exceptional reduced PAYE earnings*", one must turn to Regulation 33. This provides that "P" has "*suffered exceptional reduced PAYE earnings*" if:

> "*(a) As a result of an infection or any associated treatment, P has suffered a reduction in PAYE earnings because they can no longer–*
>
> *(i)* *perform work that is remunerated at the same level as the work they were performing before they were diagnosed with the infection, or*
>
> *(ii)* *work for the same amount of time of that they could work for before they were diagnosed with the infection,* ***and***[553]
>
> (b) the percentile of P's pre-reduction annual PAYE earnings … is
>
> …
>
> *(iii)* *where P has Hepatitis B or Hepatitis C (or both, but not HIV), at least the 60th percentile.*"[554]

It follows that the Regulations do not allow for an exceptional loss claim to be made for a person who was under 55[555] by the end of 2008 (Hepatitis B) or 2016 (Hepatitis C) unless

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[551] Emphasis added for ease of understanding.

[552] Regulation 35(1)(a) and 35(2)(a) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p35 RLIT0002944

[553] Emphasis added for ease of understanding

[554] Regulation 33(1) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp31-32 RLIT0002944

[555] Though it is not stated in these terms, the provision in respect of those who are 55 or over is made by the combination of Regulation 20(5) and (6). Regulation 20(6) provides that "*the relevant year*" is 1953 for a person infected with Hepatitis B, and 1961 for a person infected with Hepatitis C. If P was born before the relevant year they will have reached 55 by 2009 or 2017 respectively. Regulation 20(5)(a) provides that in that case, P is to receive annual amounts which continue whatever the year, until presumed retirement at 66; Regulation 20(5)(b) provides that those born after the relevant year (1953/1961) (who will therefore have been under the age of 55 in 2009/2017) will receive sums for every later year which are less than

they were a higher earner. There is no provision for the person who, by reason of the after effects of treatment or of infection or stigma or discrimination, is unable effectively to return to work.

When, following the hearings, it was put to Jame Quinault under the Inquiry Rules 2006 that the scheme did not provide for the annual reduction (under Regulation 20(6)) to be disregarded in the case of someone who was able to show that they had been unable to return to work, he responded that the scheme did indeed provide for a disregard in the case of a person who could (in the words of Sir Robert Francis) provide "... *some evidence of ongoing chronic fatigue, if that is the ground relied on*" and that "... *not all other infected persons will have been able to return to work. Accordingly, I recommend that on production of some evidence to support such a claim, such as a medical certificate, a supplementary claim should be allowed*." Indeed, James Quinault said he regarded people who were not able to return to work post treatment to the level assumed by the core award, because of stigma or chronic fatigue they experienced, as being eligible for a supplementary award. His view is that "*The exceptional reduced earnings award is often thought of as a means by which those with exceptionally high earnings can claim greater compensation, but it is also available for people who can show that they were not able to work as much as the core route assumes*."

Commentary

It makes no sense that someone treated earlier should have their financial loss affected by the fact that other people gained access to effective treatment later, nor that someone whose ability to work had been impaired by earlier treatments should be assumed to have an improved ability to work from a date unconnected with the cause of their impaired ability to work or to find work.

On the available evidence, the way the Regulations have been drafted do not (as I understand them) adequately give effect to the intention of the Government as James Quinault has expressed it. Whether this is my misunderstanding, or his, is immaterial to the essential point – there is agreement that a person who is not a "high earner" but can show that as a result of the after-effects of treatment, infection or stigma they cannot work as much as they were able to before should not suffer the reduced levels of compensation for annual losses from 2009 (in the case of those suffering from Hepatitis B) or 2017 (Hepatitis C) for which the core route provides through the mechanism of the date of effective treatment.

It needs to be made clear by a suitable addition to, or clarification of, the wording of the Regulations that this is the case.

I recommend that: For the calculation of Financial Loss awards for Hepatitis B, people born after 1953 should be treated like those born in or before 1953 on provision of evidence that their health did not improve or that it remained difficult to find work

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the annual amount provided by 20(5)(a). Regulation 20(5) and 20(6) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944

from 2009. For the calculation of Financial Loss awards for Hepatitis C, people born after 1961 should be treated like those born in or before 1961 on provision of evidence that their health did not improve or that it remained difficult to find work from 2017.

6.4 Hepatitis: deeming the level of hepatitis

Regulation 20 of the 2025 Regulations provides for the making of an "*additional financial loss (core) award*" for the purpose of compensating for past and future financial loss. For a person who has Hepatitis B or C, the amount payable depends on the level of severity of the infection, and regulation 20(6)(b) provides that:

> "*the severity of P's infection, in relation to a year, is–*
>
> *(i) the level of severity of P's infection which has been established in relation to that year to the IBCA's satisfaction;*
>
> *(ii) where insufficient evidence has been provided to establish the level of severity of P's infection in relation to that year, to be determined in accordance with paragraph (7).*"[556]

Regulation 20(7) in turn provides that:

> "*(7) For the purposes of paragraph (6)(b)(ii), where on the relevant date the severity of P's infection is—*
>
> *(a) level 2, the severity of P's infection is deemed to be level 2 for each year of P's infection;*
>
> *(b) level 3, the severity of P's infection is deemed to be—*
>
> *(i) level 3 for the 6-year period which ends with the final year;*
>
> *(ii) level 2 for every other year of P's infection which is before the final year;*
>
> *(c) level 4, the severity of P's infection is deemed to be—*
>
> *(i) level 4 for the 4-year period which ends with the final year,*
>
> *(ii) level 3 for the year 6-year period which ends with the year which is 5 years before the final year, and*
>
> *(iii) level 2 for every other year of P's infection which is before the final year.*"[557]

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[556] Regulation 20(6)(b) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944

[557] Regulation 20(7) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944

The "*final year*" for the purpose of regulation 20(7) is the year in which the relevant date falls; the "*relevant date*" is (for the living infected) the date of the person's application for compensation.[558]

Regulation 20(7) is a method for establishing the dates when changes in the level of severity of an infection are deemed to occur in the absence of evidence, but the effect of the "*relevant date*" being limited to the date of application is that severity can only be deemed about the recent past, not for a period when medical records do not exist or prior to a late diagnosis when there is no information about the extent of liver damage which may have been suffered before that point.

The written submissions on behalf of the core participants represented by Milners Solicitors state that:

> "*The effect of the deeming provisions as drafted, is that they serve only to deem periods of severity from the date of a person's application for compensation and have no use to any claimant who has some information about their severity changes but not enough to establish all of their changes of severity.*
>
> *… Applying the deeming provisions only from the date of a person's application for compensation is irrational because the deemed periods are founded on advice from an expert clinical panel about the ordinary progression of a hepatitis infection towards liver failure. By denying access to the deeming provisions to those who for instance know that they had a liver transplant in 2005 but don't know when they developed cirrhosis, is to undercompensate such a person in spite of the Government's own expert advice about when that person likely progressed from chronic infection to cirrhosis and then onwards to liver failure.*"[559]

In his oral evidence, James Quinault suggested that "*where evidence exists, the scheme takes what evidence there is and the point of the deeming provisions is to kind of step in if there is no evidence at all.*" This does not help if there is some evidence but not enough to cover the whole period. Thus, when asked about a case in which (for example) it is known when a person had a liver transplant, but it is not known what the progression of their disease was prior to that, he accepted that "*you would start from the date of application*". Asked if it would disadvantage people, he said:

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[558] Regulation 20(8) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944. See the definition of "*relevant date*" in Regulation 2 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p4 RLIT0002944. Where the person was deceased on the date of the application, the "*relevant date*" is the date of the person's death. The financial loss awards for eligible bereaved people affected are not determined by the severity of the infection of their loved one.

[559] Written Submissions on behalf of the core participants represented by Milners Solicitors para 41, para 46 SUBS0000086. See also the fictional example provided by Ben Harrison of Milners Solicitors about someone infected through a transfusion and never identified as infected until diagnosed with liver failure. He adds: "*I have dealt with a claim to the IBCA with circumstances which are somewhat similar to the fictional example given and it was confirmed to me that the Claimant would be treated as having progressed immediately from level 2 to level 4 infection.*" Written Statement of Ben Harrison paras 107-112 WITN7759001

> "*The sort of anomalous situation is where you do have some evidence, you have got evidence that people were at the highest – someone was at the highest severity band and you have a definite date of infection or a deemed – an assumed date of infection. I think then there possibly is an anomaly in that the deeming provision can't – that's the way the regulations work, can't provide for the kind of middle stage … It would make a difference* [to the amount of the compensation] *but, of course, it only applies in the case of the highest awards when people are already at the top end of what the scheme can provide. So I think there is an issue there but it's not -- you know, it's small in the context of those larger awards … .. I think in that case what we're talking about here is a significant sum of money, but it's about 3.5% of the total award.*"[560]

James Quinault confirmed this evidence in his subsequent written statement.[561]

The written submissions on behalf of the Milners Solicitors core participants suggest that it is wrong to describe this scenario as "*anomalous*", because "*there are likely to be a number of people (thinking particularly of whole blood transfusion recipients) who did not know that they had an infection until they became seriously ill and who will not have records to show the deteriorating state of their health because they were not being monitored because, in turn, they did not know that they were infected.*" The submissions also point out that this situation will not only arise in the most serious cases where people are "*already at the top end of what the scheme can provide*", observing that:

> "*To the extent that it is even relevant what proportionate difference the failure of the Regulation to engage yields, it is a significant sum of money which people ought to be receiving but which they will not …whether it makes a 3.5% difference or a 35% difference is not the point – the point is that the additional sum should be paid to the infected person.*"[562]

These concerns are echoed by other core participants. The written submissions on behalf of Thompsons Solicitors (Scotland) core participants submit that the deeming provisions "*require to be reviewed to provide more equitable results.*"[563] The submissions on behalf of the Collins Solicitors core participants make similar points about fairness and the anomalous position created for some cases by the deeming provisions.[564]

Leigh Day core participants submit that it is known that individuals were not regularly monitored and that often there will not be any evidence of progression:

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[560] James Quinault Transcript 8 May 2025 pp152-154 INQY1000284

[561] Third Written Statement of James Quinault paras 61-69 WITN7755006

[562] Written Submissions on behalf of the core participants represented by Milners Solicitors paras 48-50 SUBS0000086

[563] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.41 SUBS0000084

[564] Written Submissions on behalf of the core participants represented by Collins Solicitors paras 23-24 SUBS0000092

> "*Individuals were not regularly monitored, including being offered and provided Fibroscans/biopsies (which haemophiliacs are unlikely to receive in any event) and ultrasounds to consider progression and treated if so. Individuals were written off as alcoholics and ignored, many only offered treatment when it was urgent and even then it was not always successful.*"[565]

They propose that the relevant date for regulation 20(7) be changed from the date of application to the date of diagnosis of the qualifying condition:

> "*This would mean that the deemed years would be applied backwards from the diagnosis date and individuals would be more accurately and fairly compensated based on the presumed disease progression as advised by the Expert Group … This simple amendment would correct a significant flaw in the current scheme, ensuring that individuals are not penalised for lacking historical medical records – especially when such evidence was often unavailable due to systemic failings.*"[566]

Similarly, Thompsons Solicitors (Scotland) submit that the date "*must flow from the dates which the evidence shows that developments in an individual's condition occurred*" and Milners Solicitors submit that the provisions should apply from "*any known date of severity change.*"[567]

Commentary

In the case of Hepatitis, there are broad bands of severity of infection set at five levels to cover increasing degrees of injury, suffering and loss of amenity from least to most.[568] In the case of chronic hepatitis the appropriate band into which a given person's infection fits is likely to change over time, from bad to worse, since it is naturally a progressive disease. The scheme compensates for financial losses on an annual basis at levels which increase as these severity levels increase. The total figure for financial losses is the sum of each of the years, at the appropriate severity level for that year. Thus for this to be accurately assessed it is necessary to know, year by year, what the level of severity was during each of those years.

If adequate evidence is readily available to show the severity of the infection in each year of an infected person's life, the sums to be awarded can be accurately computed. However, in the great majority of cases there is no adequate evidence. Hence it is necessary to make an informed guess as to the likely severity level in any given year.

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[565] Written Submissions on behalf of the core participants represented by Leigh Day Appendix pp22-23 SUBS0000088

[566] Written Submissions on behalf of the core participants represented by Leigh Day Appendix p18 SUBS0000088

[567] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.42 SUBS0000084, Written Submissions on behalf of the core participants represented by Milners Solicitors para 51 SUBS0000086

[568] The fifth applicable only to Hepatitis B.

This explains the desirability of a provision, informed by clinical experience, which sets out what the best guess is, in the absence of evidence as to what, during that year, it actually was. In the absence of records such a deeming provision is a sensible response to some of the failings identified in the Inquiry Report including:

- Failing to carry out any lookback at the time universal screening of donations for Hepatitis C was introduced.
- Delaying informing people of their infection by weeks, months and sometimes years.
- Delaying telling patients they had Hepatitis C, or should be tested for it, thereby preventing the individual from controlling its worst effects and seeking timely treatment.
- Difficulties and delays in accessing appropriate specialist treatment and monitoring for Hepatitis C.
- Failures of record-keeping, such that many people's medical records have been destroyed or lost or are materially incomplete.[569]

However, to fulfil the purpose of such a deeming provision it is necessary to know what the severity level was at a given point, by reference to which the typical pattern of slow deterioration up to that point can be estimated. One such – and obvious – point of reference is the date of application,[570] for the severity of the then current infection can then be established. However, since the purpose of the provision is to provide a fair assessment of the severity level in each year of infection, so that for each year the person concerned will be paid the appropriate amount for that degree of injury, it should in fairness not be the only point of reference. If, for instance, it is known from available evidence that a person reached Level 4 infection (decompensated cirrhosis/liver transplant) in 2000, but it is not known when the person developed cirrhosis or serious fibrosis (Level 3), it would be unjust to deem that that person had had no level which could be compensable before 2000 except at Level 2. Applying that deeming date, such a person would be deemed to have gone straight from having chronic infection to needing a liver transplant, with none of the slow deterioration which would have happened before 2000. That would undoubtedly be wrong.

Back calculations from the date of application are intended to chart the progress of infection through what were probably its various stages of increasing severity. There is a risk that, instead, they force the assessor to make assumptions about the past which are improbable. If however there is evidence that a certain level of severity has been reached at a point

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[569] Infected Blood Inquiry Report 20 May 2024 Volume 1 pp5-7 INQY0001001

[570] In the current process by IBCA, no application is made until asked for: this may, albeit unintentionally, have the effect that a deeming provision taking the date of application as a reference point will tend to give less by way of compensation than if an individual was permitted to apply as soon as they wished, even if the application was not considered till later.

before the date of application, it is sensible to assume that the infection progressed naturally to that point.

Thus, where the level of severity of a person's infection at Level 3 or more has been established to IBCA's satisfaction in relation to a given year, but it is not known when it reached Level 3 or more, the legislative provisions should apply to deem the level of severity in the years which preceded that given year. It requires a simple addition to the wording to add, after "*the relevant date*" in Regulation 20(7), the following: "*or from any earlier date on which it is established to the satisfaction of IBCA that P's infection reached severity of Level 3 or Level 4, as the case may be*" (or words to that effect).

I do not, in this recommendation, add in any provision to deal with the position where (for example) a person is shown on the date of application now to have reached Level 4, but it is established that they had cirrhosis or serious fibrosis at a date more than 10 years before that. It is not necessary to do so, because once Level 3 is established to the satisfaction of IBCA[571] it is also established that in each succeeding year the infection is at least of that severity – and, accordingly, the deeming provision that provides that the severity of the infection is deemed to have been at Level 4 for 4 years, and Level 3 for 6 years before that, is displaced by IBCA's knowledge that the infection must have been at least Level 3 for every year thereafter. The evidence is that the disease, once at a given stage of progression, would not have regressed.

I recommend that: Where the level of severity of a person's infection at Level 3 or more has been established to IBCA's satisfaction in relation to a given year, but it is not known when it reached Level 3 or more, the legislative provisions should apply to deem the level of severity in the years which preceded that given year.

6.5 Hepatitis: date of diagnosis

Regulation 14(2) of the 2025 Regulations requires that an application for an infected core payment must be accompanied by evidence which (amongst other matters) establishes "*the date on which the diagnosis* [of HIV, Hepatitis C or Hepatitis B] *was given*".[572]

The date of diagnosis **with HIV** is relevant to the calculation of the financial loss (core) award for a person with HIV: this is because regulation 20(4) and (5) calculates the annual amounts for payment by reference to "*the year in which P was diagnosed as infected with HIV*".[573] The date of diagnosis **with Hepatitis C or Hepatitis B** does not, however, affect the calculation of the core award.[574]

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[571] Regulation 20(6)(b)(i) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944

[572] Regulation 14(2)(c) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp17-18 RLIT0002944

[573] Regulation 20(4) and 20(5) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp21-22 RLIT0002944

[574] The date of diagnosis can be relevant to the question of whether an application for an infected core payment has been made in time: regulation 14(1) requires such applications to be made by the end of

James Quinault's written statement refers to the need to identify the years when a person entered the higher bands for hepatitis, but (correctly) records that "*'diagnosis' here means diagnosis of these severe conditions, rather than diagnosis of the original infection.*"[575]

The Regulations thus contain a requirement for those infected with Hepatitis C or B to produce, as part of their application, evidence of a diagnosis date which is not used in calculating the core award.

The evidential difficulties in establishing the date of diagnosis should not be underestimated. As set out in the Inquiry Report:

> A very significant number of people have told the Inquiry that they were ill for many years before being diagnosed with Hepatitis C.[576]
>
> Some people were not informed of their diagnosis for a number of years after they had tested positive.[577]
>
> A number of people, particularly those who were attending medical appointments for pre-existing conditions, were not told they were being tested for Hepatitis C.[578]
>
> Others only learned about their diagnosis with Hepatitis C by chance through unrelated health checks or medical procedures.[579]

Evidence relating to people with bleeding disorders included that:

> There was a similar [to HIV] lack of any uniform approach to testing for Hepatitis C and informing patients of their test results. Some patients were tested using stored sera, often without any knowledge that sera had been stored or that tests were being undertaken on it. Others were tested using blood taken at routine appointments, unaware of the purpose of the test. The communication of test results was often delayed, with people learning that they had been infected with Hepatitis C sometimes years after they were tested …[580]

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31 March 2031, or "*if later, the end of the period of 6 years beginning with the day in which the person to whom the application relates … was diagnosed with an infection*". This will not be relevant to the vast majority of applications. Regulation 14(1) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p17 RLIT0002944.

[575] Third Written Statement of James Quinault para 48 WITN7755006, Regulation 20(6)(b) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p22 RLIT0002944

[576] Infected Blood Inquiry Report 20 May 2024 Volume 2 p28 INQY0001002

[577] Infected Blood Inquiry Report 20 May 2024 Volume 2 p31 INQY0001002

[578] Infected Blood Inquiry Report 20 May 2024 Volume 2 p36 INQY0001002

[579] Infected Blood Inquiry Report 20 May 2024 Volume 2 p38 INQY0001002

[580] Infected Blood Inquiry Report 20 May 2024 Volume 4 p366 INQY0001004

In relation to Hepatitis B, the Inquiry received evidence of people not being informed that they had been infected with Hepatitis B, or facing a long period of ill health before being diagnosed.[581]

There are also widespread difficulties in relation to medical records, as recorded in the Inquiry Report:

> The destruction and disappearance of medical records has caused both practical difficulties and significant anxieties for individuals who were infected and their family members.
>
> A number of concerns have been raised about the quality and content of medical records when records have been obtained by individuals. In particular, concerns relate to inconsistency between what is recorded in the notes and the information that was given, or not given, to a patient; and inaccurate information being recorded in the records.[582]

As the written submissions from UKHCDO explain:

> "*In the case of HCV, the financial loss (loss of earnings) award is made based on the claimant's age, the severity of their illness, and the date effective treatment was introduced. The information that is required is the fact that the claimant has HCV, the current severity of their illness … and the dates on which they moved from one category of severity to the next.* ***There is no need to know (or ask) the date of diagnosis, and yet that question is being asked, causing delay and adding to the workload of clinicians for no good reason****.*"[583]

The IBCA Policy Forum minutes of 21 March stated:

> "*Policy forum would recommend that ExCo approve the removal of diagnosis years from Hepatitis claim declaration forms, as its inclusion is unnecessary, distracting and slowing down some claims*".[584]

Commentary

In circumstances where there are already substantial delays in people receiving compensation, it does not make sense for there to be a universal requirement for people infected to provide evidence of the date of diagnosis of Hepatitis B or C – a requirement that is likely to give rise to further delays and which serves no useful purpose.

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[581] Infected Blood Inquiry Report 20 May 2024 Volume 2 pp46-47 INQY0001002

[582] Infected Blood Inquiry Report 20 May 2024 Volume 6 p283, pp299-300 INQY0001006

[583] Emphasis added. Written Submissions on behalf of the UKHCDO para 18.4 SUBS0000083

[584] IBCA Policy Forum Minutes 21 March 2025 p1 WITN7757014

I recommend that: Regulation 14(2)(c) be amended to remove the requirement for evidence of the date of diagnosis of Hepatitis B or C. An appropriate redraft to achieve this would be: "*where the diagnosis mentioned in sub-paragraph (a) is one of HIV, the date on which it was given.*"[585]

6.6 Financial and care losses

The financial loss award is described in the Government's policy paper as being "*Calculated based on the average anticipated loss of earning suffered by an infected person as a result of their infection and subsequent treatment*" and "*High Financial Loss awards will be available where applicants can demonstrate that they would have earned more than is assumed by the tariff, or were able to work less than is assumed by the tariff.*"[586]

The care award is described as "*Calculated based on a typical pattern of care needs after infection and commercial care costs associated with an Infection Severity Band of a person's infection*" and similarly "*Higher Care awards will be available where applicants can demonstrate higher care costs or care requirements than those assumed by the tariff.*"[587]

For people who choose to continue receiving support payments, "*Support Scheme payments will not be taken into account … in relation to* ***past*** *Financial Loss or* ***past*** *Care awards*".[588]

Past losses for people choosing continued support payments

People who choose to continue receiving support payments are affected by Regulation 7 of the 2025 Regulations. It contains formulae for the calculation of the "*past amount*" and the "*future amount*" of certain awards under the scheme, including financial loss awards and care awards (under both the core and supplemental routes).[589]

The formula for calculating the past amount of these awards is:

> $x \times ((Y2 + 0.25) \div Y1) \times T$,[590] where:
>
> "T" is the amount of the award in relation to P (the eligible infected person).

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[585] This is suggested by Milners Solicitors and it meets the objective. Written Submissions on behalf of the core participants represented by Milners Solicitors para 37 SUBS0000086

[586] Infected Blood Compensation Scheme Summary 31 March 2025 p16 RLIT0002481

[587] Infected Blood Compensation Scheme Summary 31 March 2025 p15 RLIT0002481

[588] Emphasis in original. Infected Blood Compensation Scheme Summary 31 March 2025 p35 RLIT0002481. For future payments "*IBCA will compare the future financial loss award and future care award under the Scheme with the person's estimated Support Scheme payments up to their healthy life expectancy … For infected IBSS beneficiaries, where the awards under the Scheme are higher than the estimated Support Scheme payments, the person will receive a 'Support Scheme top up award' which will be added to the compensation paid by IBCA. If the awards under the Scheme are lower, this will have no impact on the Support Scheme payments …*"

[589] The awards to which Regulation 7 applies are listed in Regulation 7(1) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p13 RLIT0002944

[590] Regulation 7(2) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p13 RLIT0002944

> "x" is 0.75 if Regulation 7(5) applies,[591] and otherwise 1.
>
> "Y1"is the number of years in the period which begins with P's first year of infection and ends with the year in which P attained, or is expected to attain, the age of their healthy life expectancy.[592]
>
> "Y2" is the number of years in the period which begins with P's first year of infection and ends with 2024.[593]

This can be expressed in words as the ratio of the number of years someone has spent infected up until March 2025 to the number of years they live with the infection and its consequences until their healthy life expectancy. This is to be reduced to 75% for someone who opts to continue receiving support payments.

Since "x" only applies to people who continue in receipt of support payments, the effect of this formula on the face of it may seem to be that they receive a quarter less compensation for their past care costs and past financial losses than those who do not choose to continue to receive support payments. It therefore requires explanation.

Lawyers assisting individuals with the determination of their compensation claims by IBCA have raised concerns about the way in which this calculation works.

Ben Harrison (of Milners Solicitors) uses a fictional example of "Mr Smith" to illustrate the position.[594] As he explains, Mr Smith's past financial losses could easily be worked out by adding together the three periods between 1976 and 2024 to arrive at a figure of £996,482. However, Regulation 7 does not permit past financial losses to be calculated in this way – instead the equation set out above must be applied. Application of this equation produces a past financial loss in Mr Smith's case which is £58,397.13 less than that arrived at through simply counting up the appropriately rated years between the infection and 2024. He explains further that the equation always delivers a figure less than one would arrive at by a simple counting up of the relevant years at the relevant rate, and that the discrepancy between the two methods of establishing past financial losses increases the younger the claimant is.[595]

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[591] Regulation 7(5) applies if the past amount of a care (core) award, care (further core) award, care (severe health condition) award or care (further severe health condition) award is being determined in relation to a person infected in receipt of support scheme payments. Regulation 7(5) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p14 RLIT0002944

[592] "*healthy life expectancy*" is calculated by reference to projected life expectancies in the actuarial tables published by the Government Actuary's Department for use in personal injury and fatal accident cases. Regulation 2 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p3 RLIT0002944

[593] Regulation 7(4) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p14 RLIT0002944

[594] The example is this: "*Mr Smith was born in 1960 with a bleeding disorder, he was infected with Hepatitis C through the use of FVIII in 1976. In 1998, he was diagnosed with cirrhosis and in 2004, he received a liver transplant. Mr Smith is expected to retire in 2026 and to live until 2046. He is accepted by the IBCA as eligible to claim at HCV Stage 4 and invited to make his claim in December 2024.*" Written Statement of Ben Harrison para 91 WITN7759001

[595] Written Statement of Ben Harrison para 96 WITN7759001

The calculation results (in effect) in a reduction of the past financial loss award for a person who chooses to keep receiving support payments.

The concern expressed on behalf of the core participants represented by Milners Solicitors is twofold: first, that the regulation does not achieve what was promised to people infected and affected because it runs contrary to the Government's response to Sir Robert Francis' recommendations in August 2024, when the Government said that "*Support scheme payments will not be taken into account … in relation to past financial loss or care awards*";[596] and second that it is unnecessary to include a complex calculation using a convoluted mathematical equation when one can just arrive at a fair figure by adding up the amounts stipulated in the Regulations for each of the past years.[597]

In relation to the calculation of past care awards, Ben Harrison acknowledges the probable need for an equation to calculate these but suggests that "*the equation which has been arrived at weights too much of the award to future care costs and is not generous enough in relation to past care costs.*" He explains "*In my experience, the equation typically yields past care awards of less than 50% of what the total award would be. To my mind, this is unlikely to reflect the reality for many …*"[598]

Similar concerns are voiced by Gene Matthews of Leigh Day in respect of (first) financial loss and (second) care costs. He observes that the formula ensures that a percentage of the past financial loss is deducted "*directly contradicting the statements … that confirm the IBSS payments will only be taken into account in respect of future financial loss alone.*"[599] He adds in relation to the care award that it is unclear "*why the past care award is deducted under the IBSS Route only*".[600]

James Quinault on behalf of the Cabinet Office suggests that the scheme uses a standard formula when splitting past and future financial loss and care awards for "*the sake of simplicity and consistency*" and records that "*the Government does not believe this is discriminatory, or that taken as a whole, the Scheme is underpaying for past losses.*"[601] In his oral evidence, he said, in relation to financial loss:

> "*I understand the point the recognised legal representatives are making, which is that if you do as the calculation does and take an average across the whole of that period, you are arguably under-representing the past loss because that average also includes some years when people will be getting a pension rather than full earnings, and I think that is a fair point to make. But what I would say is, I do not believe that, overall, this approach is disadvantaging people or is, you know, not fulfilling the Government's promise to make sure that people's*

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[596] Government Update on the Infected Blood Compensation Scheme 16 August 2024 p8 WITN7760006

[597] These concerns are echoed by Patrick McGuire of Thompsons Solicitors (Scotland). Written Statement of Patrick McGuire para 55 WITN7760001

[598] Written Statement of Ben Harrison paras 101-102 WITN7759001

[599] Written Statement of Gene Matthews para 66 WITN7762001

[600] Written Statement of Gene Matthews para 64 WITN7762001

[601] Second Written Statement of James Quinault para 187, para 191 WITN7755003

> *past compensation is not affected if they take the support payments route … It would have been possible for the regulations to do as the RLRs suggest and to take a different approach and to build up the financial loss award kind of year by year, but I think while that might have looked more precise, I don't think it would actually be more accurate.*"[602]

Commentary

Regulation 15 of the 2025 Regulations sets out the component parts which when taken together make up the core award for someone infected.[603] So far as financial loss and care awards are concerned it draws a distinction between someone who opts to continue support payments, and someone who does not. The person who chooses the support payments route receives a core sum composed of their past financial and care losses, together with a Support Scheme top-up award. (This is meant to ensure that if they opt for support scheme payments they will be no worse off than they would have been if they had chosen to have their future financial loss calculated by the scheme. It is of no further relevance to this chapter.) For the person who is not going to receive support payments in future, no distinction is made in Regulation 15 as between past and future care costs and between past and future financial losses – it is not drafted such that an individual opting for a lump sum payment is said to receive the sum total of (a) past and (b) future losses. Instead, so far as care is concerned a single figure is awarded for the totality of the care costs across the lifetime of someone infected and financial loss is not calculated as past and future losses either.

Thus no easy direct comparison can be made by looking to see what someone opting for a lump sum payment is to be awarded for the past, by comparing it to what someone continuing with support payments is to receive for the past, because the award of the person opting for a lump sum payment is not split into "past" and "future" portions.

Because people infected do not have to credit past support scheme payments against their awards, it is not necessary to involve these payments in any calculation of past losses. Nor is it necessary to take account of them where an infected person is not going to receive them in future. Accordingly, the past amount of financial loss and care loss has specifically to be calculated only for the purposes of ensuring that someone infected who is in receipt of support payments is properly compensated for the past – the future care costs and financial losses, broadly, being compensated for by the scheme.

The past loss figure is calculated by working out what was the proportion of an individual's expected "infected life"[604] that they had lived by the end of March 2025, and applying

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[602] James Quinault Transcript 8 May 2025 pp150-151 INQY1000284

[603] Regulation 15 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp18-19 RLIT0002944

[604] That is not a phrase used in the Regulations, but it is adopted because it represents what the regulations provide. There are essentially two figures - the length of time a person would have expected to live if uninfected, starting with the date of the infection; and the length of time between that date and the end of March 2025. The proportion of the expected lifespan which has been taken up by the years since infection can then be worked out, and applied to calculate what is a past loss (i.e. a loss prior to the end

that proportion to their lifetime financial losses and care costs. With the exception of the "x" in the daunting formula set out at the start of this chapter, that is what the equation means to achieve.

The question is: why should this proportionate calculation be reduced by applying the "x" factor? There may be different reasons in respect of financial loss on the one hand, and care costs on the other. If there are different reasons, then one may have greater validity than the other.

So far as financial losses are concerned, a practical problem is that financial losses aggregated over a lifetime will vary, year by year. A tariff scheme recognises that most of these year to year changes depend upon life events which may or may not happen – the effects of promotion on the one hand, redundancy on the other; the availability of overtime on the one hand, against the reductions in income which may come with accommodating a change of location, and so on. These uncertainties mean that precise figures even of past loss, but certainly of future loss, can never be exactly calculated, and that it takes a large amount of time, trouble and cost to calibrate it more precisely to any given individual. Thus a tariff scheme properly makes generalised assumptions to reach across-the-board figures. These are necessary to do broad justice, whilst ensuring speed of delivery, an easier calculation, and an efficient use of resources. However, there are some events which create such a large step change in income that they cannot easily be rolled up in an annualised figure which assumes only small changes, if any, from year to year. These large changes, which will occur in the lifetime of almost all people, may have to be recognised. One is that in retirement a person may expect to receive a pension which is likely to be substantially less than the sum earned annually before retirement whilst working in a paid role. Thus a tariff scheme assessment of future loss, which is worked out by applying the same annual figure of earnings to every year of life, may have to be adjusted to reflect what will almost inevitably be reduced income in retirement years. The same will apply, of course, in respect of people who are infected whilst they are in their first few years after entering the labour market on reaching 16 – years of training, further education, or apprenticeship, as well as tending to start working life in lower paid work and working up swiftly to a lifetime rate that is likely to continue. They too may require an adjustment to a figure for annual earnings which broadly reflects the pay of someone established in work.

So far as reduced earnings in retirement are concerned, this is recognised in the scheme by adopting a figure of 50% of the annual loss for each year after the year in which the recipient will (or did) turn 66. In short, both in respect of younger and older ages there may be particular reasons for thinking that an annualised sum paying the same for every year, young or old, may be higher than would in practice be received.

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of March 2025). An example to illustrate this is – take a person, A, who was born 50 years ago. Take their approximate healthy life expectancy as being 80. They still are expected to have 30 years to live. Suppose 30 years ago they were infected. The proportion of their anticipated lifespan for which they have been infected will be 50% (the proportion 30 years bears to the life expectancy at the date of infection which would be 60 years). Thus the equation begins by assuming that in those 30 years the average loss per year is the same average loss as it will be in the years to come.

If one begins with the assumption that the annualised figure for earnings loss is a fair one, then both those people who are in receipt of support payments, and those who were not, would have suffered that loss. It would be less than fair to count the loss as being lower. The support payments are, rightly, not to be taken into account. There is no obvious reason why a person's choice should make any difference to the annual earnings loss itself. It is not a feature such as retirement on a pension, or lower earnings as a student, which could have any bearing on income. The effect of the multiplier ("x") is to reduce the notional earnings of people who choose to continue receiving support payments, whilst not reducing the notional earnings of people who do not in respect of an identical period. It means that less than a fair figure appears to have been applied to the first group.

Since in the case of financial loss it is possible to compare like with like (year with year) in a way that cannot be done with care costs, it is clear that the person not in receipt of support payments is paid one third more in respect of their past loss than is the person receiving support payments. This looks like a classic case of inconsistent treatment, favouring one group for a reason which has nothing to do with whether they could have earned more or less if uninfected.

It is difficult to understand the rationale for this. It could simply be adjusted by removing the "x" in the case of financial losses.

So far as care costs are concerned, the scheme treatment of these raises different issues. Because the person who does not choose to continue receiving support payments is given one lump sum to cover both past and future losses, it is not possible to compare their position year by year with the person who decides to continue receiving them. It may be that the model applied to calculate the lump sum assumes a lower rate in respect of compensating for care in the earlier part of the period, and a higher rate for later years. If this were so, then the value of the care given in the years before March 2025 might be lower per week, month or year over the whole of this earlier period than it is anticipated it will be in future. If this is the model, the reason for it is not apparent on the face of the Regulations.

The way the equation works, it is assumed that the value of care given to people infected was lower per week, month, and year before March 2025 than the cost of care will be after that date. This is difficult to square with the evidence before the Inquiry as to what happened in the past. People who were infected with Hepatitis in the 1970s will have had increasing demands for care as their Hepatitis progressed. Though symptoms may not have been as pronounced in the first years of chronic infection, after a while their needs for care increased markedly – especially for those who then underwent treatment with interferon before 2016. Much of the evidence recorded that their experiences were particularly brutal during the 1990s, and these continued well into the 2000s. With the intensification of symptoms there inevitably came a greater need for care. The evidence suggests that experience of modern DAA drug regimes has been significantly different.

On the basis of the evidence of what people themselves suffered, there is a strong case that more care was needed, at less convenient times, and in more stressful situations in the past than is likely to be needed in the future. In particular, more care is likely to have been needed during the period when the treatments for Hepatitis and HIV were particularly difficult to tolerate. These treatments came with side effects of unpredictability of behaviour and mood of a kind that make significant demands on carers. They did not simply demand greater care in terms of hours spent. The care required was different in quality – it was inevitably more intense, and is certain to have imposed greater demands on the caregiver than ordinary domiciliary care would do.

There is an indication in the scheme that it recognises that the future for those treated effectively for Hepatitis will create less demand for care – it provides that the annual loss of income for years "after the year of effective treatment" (2016 for Hepatitis C, 2008 for Hepatitis B) will be half that which was the previous annual loss. The assumption is that a person, if effectively treated by direct acting antiviral drugs,[605] would be significantly more able to work after then. It might be thought that if that is so, then the need for care attributable to the infections and their consequences will also be at a reduced level in the future compared to that which it was beforehand, since it is an accepted generalisation that people who are fitter to work are less likely to need personal care.

There are three matters which need to be taken account of in working out the value (or cost) of care over any given year. One is the "unit cost" (the value/cost per hour). The second is the number of units (the hours, days etc.) for which care was needed. The third relates to how intensive the care needed to be – the nature and quality of it.[606] There are thus three questions – "How much care"?, "How much per hour"? and "Of what sort?" When James Quinault in his evidence spoke of a standard formula, he was most probably speaking of the way in which in serious personal injury cases in England and Wales the cost per hour of commercial care is taken as the starting point for asking how much the carer receives per hour in their pocket for the work they do.

He explains that the core route takes a figure calculated across a lifetime, standardised for ease of calculation. It assumes that all care, in whatever year, would have been paid for at 2023-2024 commercial rates. He points out that care awards to the deceased infected are (necessarily) all in respect of past care, and are likely to cover care provided gratuitously.[607] I accept that in personal injury cases a standard way of assessing the value of care is to ask what the caregiver would expect to get in their pocket after tax and national insurance had been paid, and any agency fees, overheads and obligatory pension provisions (and in some cases travel) had been allowed for. The starting point is to ascertain what it would cost commercially to obtain the care, per hour – and then to deduct from that figure a proportion to allow for these taxes and overheads, to reach a nominal "in the pocket" value per hour for that care. A standard allowance is typically between 20 and 25% (sometimes though

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[605] The years chosen relate to the dates these came into widespread use.

[606] Care given to cope with unpredictable behaviour is necessarily unpredictable; care at anti-social hours on demand comes at a significantly higher cost than more usual commercial domiciliary care packages allow for.

[607] Second Written Statement of James Quinault para 172, para 175 WITN7755003

rarely 30%) against the starting cost per hour. That explains why, as a result of another Regulation, a 25% deduction is made in respect of care given to the deceased infected.[608]

It also is his explanation as to why it should apply to living infected people: he says that "*To ensure consistency on how the scheme treats 'past care' throughout the scheme, the award for past care made to applicants who choose the IBSS route is also discounted by 25% to ensure the scheme is treating these split-out awards for past care in the same way for living and deceased individuals.*"[609]

This rationale is understandable in respect of care costs, per hour, but that answers only part of any assessment of how much care costs an individual. It does not address the question how many hours are needed – the "how much care" question. That too needs to be addressed if there is to be a fair assessment of what should be awarded. The "How much care" assumes that it is care of a standard sort – some care is not, for instance, given in standard day time hours, to compliant patients, with predictable demands for it. To the extent that care is given at unsocial hours, to difficult patients, and is unpredictable in much of its nature it would attract a higher rate per hour. None of the explanations given for the "x" factor being used in respect of past care costs addresses the "How much care?" and "Of what sort?" questions.

In summary, the reason for introducing an "x" factor in respect of the value of past care is not spelt out in any document, and the reason advanced by James Quinault addresses only part of the costs of care (the "How much per hour?" question). It is likely that if there had been substantial interaction and involvement between experts such as those in the Expert Group and members of the infected blood community at a formative stage of the Regulations it would have been appreciated that the need for care, whether notionally provided commercially or gratuitously, was greater in the past than it is likely to be in the future;[610] and the inconsistency between the Regulations providing for a reduced rate of earnings loss after 2008 for Hepatitis B and 2016 for Hepatitis C whilst in effect saying that future care will be more costly than past care would have been obvious, and would have been avoided.

Moreover, the rationale for applying the "x" factor to the past earnings of people who opt to continue receiving support scheme payments, but not adjusting awards in respect of exactly the same time periods for those who will not be in receipt of support scheme payments remains totally unclear. It is not addressed by any standard or conventional reduction factor of which I am aware. The suggestion that it is for "*simplicity and consistency*" with care awards, as explained by James Quinault, does not clarify matters. Why should care awards be consistent with financial awards when they deal with very different losses? How can

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[608] Regulation 21(4) compared to Regulation 21(3) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p23 RLIT0002944, Second Written Statement of James Quinault para 172, para 175 WITN7755003, Second Written Statement of James Quinault para 175 WITN7755003

[609] Second Written Statement of James Quinault para 176 WITN7755003

[610] Except in respect of end of life care, where there may be significant needs to be addressed.

care costs be treated consistently with financial losses when the latter are calculated year on year, yet care costs/values are given a lifetime figure which has then to be split into two parts? If consistency is a valid reason, why is the treatment of the care costs treated inconsistently by reducing the amount in respect of those who do opt for support payments but not for those who do not?

I recommend that: "x" be removed from the equation set out in Regulation 7.

Exceptional reduced earnings

Part of the supplementary route introduced in the 2025 Regulations is the "*exceptional reduced earnings*" award. The requirements for this award are set out in Regulations 33, 35, 37 and 38. To qualify the annual earnings prior to infection must have been 60th percentile if the person has Hepatitis B or C and 75th percentile if the person has HIV, and the application must be accompanied by evidence which establishes the actual gross earnings in the years before and after their earnings were affected.[611]

The proposals published by the Government on 21 May 2024 described the supplementary route in the following terms:

> "*In exceptional cases, where an applicant can demonstrate that their circumstances necessitate compensation beyond that offered through the Core Route, a Supplementary Route will be available. The Supplementary route may involve a personalised assessment or require the applicant to provide additional information to ensure that the compensation paid through the Scheme is appropriate to the individual's specific circumstances … Examples of where the Supplementary Route may be required include: … cases where a person was a high earner prior to infection and therefore suffered greater financial losses through lost income.*"[612]

In its policy paper published on 23 August 2024, the Government said of the supplementary route that:

> "*In some exceptional cases, the level of compensation awarded through the Core Route may not be sufficiently reflective of the financial loss … that a person has experienced as a result of infected blood. This may be the case where, for example, the person had particularly high earnings prior to their infection and therefore suffered greater financial loss … Where an applicant can demonstrate that their defined circumstances necessitate a higher compensation payment for … financial loss, they will have the opportunity to apply for additional compensation awards through the Supplementary Route.*"[613]

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[611] Regulations 33, 35, 37-38 of the Infected Blood Compensation Scheme Regulations 2025 pp 31-42 RLIT0002944

[612] Infected Blood Compensation Scheme Proposal Summary 21 May 2024 p10 RLIT0002493

[613] Infected Blood Compensation Scheme Summary: August 2024 pp13-14 RLIT0002945

The Government's Update on the Infected Blood Compensation Scheme published on 31 March 2025 describes this as an award "*to recognise where someone was a high earner or whose capacity to earn was significantly less than the core route assumes.*"[614] This reflects what the Minister told the Delegated Legislation Committee when it considered the draft regulations on 24 March 2025: "*where someone can evidence additional financial loss, most likely as a result of being a higher earner … due to their infection.*"[615]

The written submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) state that the supplementary route is "*too narrow*" and has "*deviated too significantly from its original purpose, namely allowing applications based on 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*".[616] In relation to the exceptional financial loss award, they submit that the evidence requirements will preclude access to the award "*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 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.*"[617] The core participants represented by Leigh Day echo this concern: "*The enhanced Financial Loss Award is currently too narrow for individuals infected as children who were unable to begin or build a career.*"[618]

Mono-HCV Infected Haemophiliacs, a group of around 50 people with haemophilia who were treated with blood products on multiple occasions and infected with Hepatitis C, describe the difficulty of meeting the evidential requirements for exceptional reduced earnings:

> "*As haemophiliacs, most of us kept our conditions secret when seeking employment … we soon learned it was best not to mention our condition at all … But the treatment of hepatitis was harder to disguise. Dealing with one or the other was manageable for some, but together, we didn't stand a chance … Treatment of hepatitis on top of haemophilic issues became too much for many of us and careers came to an end … We make one simple ask that the second set of regulations are amended for some discretion through IBCA to look at the financial loss for mono-HCV haemophiliacs whose education and or career was disrupted, without the requirement to produce five years worth of payslips which for many is untenable.*"[619]

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[614] Infected Blood Compensation Scheme Summary 31 March 2025 p23 RLIT0002481

[615] Hansard Delegated Legislation Committee 24 March 2025 p2 WITN7760004

[616] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.45 SUBS0000084

[617] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.48 SUBS0000084

[618] Written Submissions on behalf of the core participants represented by Leigh Day para 50 SUBS0000088

[619] Letter from Mono-HCV Infected Haemophiliacs to Sir Brian Langstaff 28 March 2025 pp3-5 WITN7765002

A discrete issue in relation to Regulation 33 was raised before the May 2025 hearing: whether a literal reading of the words "*before they were diagnosed with the infection*" excluded entitlement for those who (for example) were able to work at a well paid level after they were infected but whose ability to continue that work was then impacted by (say) developing AIDS or undergoing treatment with interferon. This would obviously have created an anomalous and unfair situation. As the Inquiry understands the position, IBCA has taken a purposive rather than literal approach so that a person in such a situation is not "*debarred from applying to the supplementary route*"[620] and James Quinault confirmed in his oral evidence the Cabinet Office's agreement with this approach.[621]

Commentary

Given that a sensible and fair approach, based on the intention underlying the Regulation rather than a literal meaning of some of the words used, appears to be being taken to recognise demonstrable exceptional reduced earnings stemming from infection or treatment, I do not propose to make any specific recommendation about that provision of Regulation 33.

The question of whether a person infected as a child would have had a higher earning capacity than the formula "average earnings plus 5%" represents, which they have never been able to realise because infection disrupted their schooling and limited their opportunities to obtain well remunerated employment, is not a new question for personal injury lawyers.[622] It is unusual for there to be any evidence which will show on balance of probabilities that earnings would be any higher – or any less – than median earnings.[623] In cases however where a person has entered into further or higher education with a view to a particular career, there may be some evidence of higher than average earnings potential.[624] While the frustration of individuals – that they were unable to realise their potential because of infection, or that they were unable to establish themselves in a career to which they aspired (which might have been better remunerated than most) – is real, I do not think there are sufficient grounds here for me to suggest that the entirety of the provisions for exceptional reduced earnings are unjust. They do have stringent evidential requirements, which are not in themselves unwarranted but there are likely to be some potentially meritorious claims which are effectively excluded. For instance, someone who has started professional training

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[620] See, for example, an email from an IBCA claim manager 24 April 2025 DHOL0000002

[621] James Quinault Transcript 8 May 2025 pp155-157 INQY1000284.

[622] In the case of the scheme it is average earnings plus 5%, but the principles are the same.

[623] There can be exceptions to this. In the case of people infected in childhood it may be the case that they have been able despite all the difficulties to obtain an offer of a well-paid job – and then, because of the debilitating effects of treatment, or the progression of disease, or simply the fact that an employer's medical check revealed the infection and the job opportunity was then withdrawn. In such a "for instance" case, there has understandably been no track record of high earnings, but the probability is that there would have been if that person had been uninfected.

[624] A student, for instance, whose course results show them on course for a top class degree, or a postgraduate who is studying for a professional qualification with an eye to later employment will have no track record of higher level earnings, but might nonetheless have significant evidence to show they had a realistic prospect of these.

with every apparent prospect of succeeding but is infected and unable to pursue their career will find it very difficult to comply with these evidential requirements.

Though the provisions apply to the generality of cases, they thus do not fit some other circumstances which are not uncommon. It may be that real cases, which are currently excluded by the narrow evidential criteria, could be accommodated. I have in mind cases where the evidence is strong that the potential for higher than average earnings was real, but the infection or the side effects of its treatment happened too early in life (or in working life) or in family life to enable the infected person to establish the significant earnings pattern that appears to be a prerequisite of such a claim.[625]

I note also that the evidential threshold could prove difficult in some other cases too, for instance, someone whose business was bankrupted many years ago in direct consequence of the impacts of infection and/or treatment, who had no reason to retain full records for a compensation scheme decades in the future when there seemed no prospect of this at the time.

I recommend that: The Cabinet Office consult on whether the evidential requirements for exceptional reduced earnings are likely to prove a barrier to people who have sufficient evidence that their eligibility for such an award could with confidence be established on a balance of probabilities, and if so to consider what if any provision might be introduced to enable them to access an award.

6.7 Unethical research

The 2025 Regulations introduce, as part of the supplemental route, an "*unethical research practices award*", payable where an eligible infected person "*was subject to unethical research practices within the meaning of regulation 26*".[626] Regulation 26 gives the following explanation of "*unethical research practices*" for these purposes:

> "*(1) An eligible infected person was subject to unethical research practices if they attended Lord Mayor Treloar College as a student at any time during the period beginning with 1970 and ending with 1983.*
>
> *(2) An eligible infected person was also subject to unethical research practices if they received treatment for a bleeding disorder –*

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[625] Personal injury lawyers in England and Wales are familiar with awards for "loss of earning capacity" which represent an injured victim's loss not so much of earnings but of the capacity to earn them. It is known conventionally as a "*Smith v Manchester*" award. Employment lawyers are familiar too with the difficulties that people on whom the burdens of child-raising fall (especially women in current society) may have in establishing a settled earnings pattern until a little later in working life. People raising a family, for instance after a transfusion in childbirth has infected them with Hepatitis, may find their earning capacity on the open labour market had been significantly reduced. They may have taken some years out of a full time job, and find they cannot after that obtain one they might if uninfected reasonably have been expected to do. Depending on the strength of the evidence in showing it, some award to reflect this loss of capacity might be just. It might however be precluded at present by the evidential requirements discussed in this chapter.

[626] Regulation 25(1)(a) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p26 RLIT0002944

> (a) *at any of the institutions listed in paragraph (3) during the period beginning with 1974 and ending with 1984, or*
>
> (b) *whilst they were subject to research led by Dr John Craske during the period beginning with 1974 and ending with 1984.*"

The institutions referred to are the following haemophilia centres: Cardiff, Edinburgh, Glasgow, Manchester, Newcastle, Oxford, Royal Free, Sheffield and St Thomas'.[627]

The amount of the award is £15,000 for someone who attended Treloar's, and £10,000 in all other cases.[628]

The origins of the award

In his report of 12 July 2024 Sir Robert Francis observed that:

> "*So far as I can tell, the proposed award for autonomy was not intended to include an element for* [unethical research] *and, as I understand it, the advisory group did not take this aspect into account in their recommendations. Not all victims will have been part of a distinct research project. The reported experiences inflicted on the children at Treloar's is perhaps the most striking example, but the Inquiry report highlights others. It seems to me that the insult of being subjected to unethical research without consent or warning is an invasion of victims' human rights which deserves compensation and explicit recognition. It should properly be considered as an element of the autonomy award, but as a specific additional element over and above the generally recommended tariff award for the generally experienced invasion of autonomy by being treated with an infected product. Should an award not include this as an element in appropriate cases, there is an increased risk that members of the infected community who were subjected to research will feel inadequately recognised.*"[629]

Sir Robert suggested that it would be appropriate to add "*a modest sum*" of £10,000, and £15,000 in the cases of children subjected to research while resident in an institution (such as Treloar's), and said that the views of the Expert Group and of the infected community should be sought.

The Government accepted this recommendation.

On 5 December 2024 the Cabinet Office issued an unpublished factsheet explaining its plans for this additional award and seeking feedback (to be provided by 19 December 2024)

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[627] Regulation 26 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p27 RLIT0002944. The official copy of the Regulations states "*paragraph (2)*" but it refers to (3).

[628] Regulations 27 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p27 RLIT0002944

[629] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 pp47-49 RLIT0002466

"*as to the identity and dates of such projects*".[630] Two specific questions were posed: the first related to the appropriate date range of studies and whether there were studies mentioned in the Inquiry Report before or after that range (1974-1984); the second related to treatment centres where unethical research took place and asked if there were additional centres mentioned in the Inquiry Report beyond those that had been identified by the Government.[631]

In January 2025 the Cabinet Office, having considered the feedback received, issued an update, explaining that the date range remained unaltered but that four additional centres would be included (St Thomas', Cardiff, Manchester and Sheffield).[632]

James Quinault told the Inquiry that in designing the award following Sir Robert Francis' recommendation, the Government "*looked for unethical research studies explicitly identified in the Inquiry's Report,*" whilst understanding (he said) that the Research section of the chapter on *Haemophilia Centres: Policies and Practice* of the Inquiry Report was not intended to be exhaustive.[633] He explained further that "*the definition of research for this purpose is any studies where the intention was to publish the results*", noting that "*The Cabinet Office understands this definition to be in line with the Inquiry's Report and with the Report of the Inquiry's Medical Ethics Expert Group.*" For this reason, he said, the request in the 11 January 1983 letter from Professor Bloom and Dr Rizza to all haemophilia centre directors[634] was not regarded as research, because the Cabinet Office did not find evidence that Professor Bloom and Dr Rizza intended to **publish** findings from the work ("*Had this work been subject to a study protocol it would have been included in scope*").[635]

Requiring evidence of an intention to publish results is not consistent with the advice that the Cabinet Office received from the Expert Group: "*The criterion we advise using to determine eligibility covers studies that altered treatment of patients without fully informed consent through which participants chose to accept the risks.*"[636] This is consistent with the Inquiry Report:

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[630] Cabinet Office Update on Unethical Research Awards January 2025 p1 WITN7754021, Infected Blood Compensation Scheme Unethical Research Awards 5 December 2024 WITN7755004

[631] The Government identified Oxford, Edinburgh, Newcastle, Royal Free and Glasgow in this factsheet, as well as evidence of being part of one of Dr Craske's studies. Infected Blood Compensation Scheme Unethical Research Awards 5 December 2024 WITN7755004

[632] Cabinet Office Update on Unethical Research Awards January 2025 p2 WITN7754021

[633] Second Written Statement of James Quinault paras 103-114 WITN7755003

[634] This letter stated that "*Although initial production batches may have been tested for infectivity by injecting them into chimpanzees it is unlikely that the manufacturers will be able to guarantee this form of quality control for all future batches. It is therefore very important to find out by studies in human beings to what extent the infectivity of the various concentrates has been reduced. The most clear cut way of doing this, is by administering those concentrates to patients requiring treatment who have not previously been exposed to large pool concentrates.*" Letter from Professor Bloom and Dr Rizza to all Haemophilia Centre Directors 11 January 1983 HCDO0000252_042 (letter misdated 11 January 1982).

[635] Second Written Statement of James Quinault paras 117-119 WITN7755003

[636] Infected Blood Inquiry Response Expert Group Addendum to Final Report 12 February 2025 p22 WITN7762015. The Expert Group first discussed the issue on 1 August 2024 and noted that in terms of research "*it represents a different era, and applying broad brush strokes could fail to address the underlying issues adequately*" but "*It was concluded that any advice needed to sit within SRF's recommendation and that expanding on this topic falls outside the scope of the Expert Group's work.*" Minutes of the Infected Blood Inquiry Response Expert Group 10 July 2024 p45 CABO0000925

> (1) Research was conducted when it exposed patients to a greater risk of harm than they should have faced, in the light of the best available medical knowledge at the time, without there being any commensurate benefit **for them**.
>
> (2) This was done without (a) (in many cases) telling patients that research was being conducted, and (b) (in most cases) giving the patient sufficient information on risks, benefits and alternatives to enable consent to be properly given …
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> …
>
> These failings have been aggravated by the way in which previously untreated patients – in particular children – were sought out to become the subject of research, and in some cases to be given treatments which were unnecessary, or conferred no advantage but only additional risk. The ethics of this are clear. It was, and is, unacceptable.[637]

The definition of research used by the Cabinet Office – requiring evidence of an intention to publish results – is too narrow and is based on a misreading of the Inquiry Report. It may be that what the Cabinet Office had in mind is the following sentence from Volume 4:

> The ethics experts told the Inquiry that, in general, if the clinician is thinking of publishing the results, it is usually considered to be research – "*if it's been published in a journal, it's original knowledge*".[638]

However, this was not intended as an exhaustive definition of research. Rather – as the context of the ethics panel discussion on this point makes clear – the publication, or intended publication, of results is **one way** of determining that it is likely to be classed as research. Logic and common sense both indicate, however, that something can be research without an intention to publish: a clinician might (for example) undertake research out of curiosity, to prove or disprove a theory, to enhance their own or their colleagues' knowledge and understanding, or because of donations by a pharmaceutical company to their research fund.

As one example (and an example which also indicates the importance of not having a rigid date range), Luke O' Shea Phillips was diagnosed with mild haemophilia at the age of one. A medical record from November 1984, when he was three, noted "*No blood products*".[639] A letter from the consultant treating him at the Central Middlesex Hospital, dated 12 June 1985, to Dr Peter Kernoff at the Royal Free Hospital (which was a centre heavily involved in research, as the Inquiry Report describes) described treating "*two virgin haemophiliacs with alpha heat treated FVIII*". In relation to Luke the letter says "*This boy also was a virgin and*

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[637] Infected Blood Inquiry Report 20 May 2024 Volume 4 p309 INQY0001004

[638] Infected Blood Inquiry Report 20 May 2024 Volume 4 p269 INQY0001004, Medical Ethics Expert Panel Transcript 27 January 2021 pp119-120 INQY1000091

[639] Extract from the medical records of Luke O'Shea Phillips 19 November 1984 WITN1696003

had never received any blood products in his life … Both patients will attend for fortnightly follow-up blood samples, for liver function tests, blood counts and virology. I hope they will be suitable for the heat treated trial." The letter was copied to Ian Marshall of Alpha Therapeutics.[640] There was no discussion with Luke's mother about any risks of infection, no discussion about alternative treatments, and no discussion about any kind of trial. Had there been, Shelagh O'Shea told the Inquiry "*I would have picked my child up and walked out of that hospital.*"[641] Luke was infected with Hepatitis C. He says: "*I have the proof that I was subjected to something that should never have happened to any human being, let alone a child. And yet, despite this evidence, I am still being treated the same as everyone else … This is more than painful. It's life-destroying. And it's not justice.*"[642]

The Cabinet Office has suggested that:

> "*If more evidence is provided in the future on additional centres the Government is committed to assessing any new evidence to ensure the full eligible list reflects where unethical research took place. Any changes would require additional new laws.*"[643]

It was suggested to Nick Thomas-Symonds during his oral evidence that – rather than people having to persuade the Government to legislate to add new centres – it would be easier if a person could go to IBCA and demonstrate to IBCA's satisfaction that they had been subjected to unethical research. This would require a single amendment to the Regulations conferring a discretion on IBCA to make the unethical research practices award to an infected eligible person where there is evidence that the individual was the victim of such practices. The Minister told the Inquiry he was "*more than happy*" to look at that.[644] In practice this would be no different from the other awards for which IBCA has to assess the evidence to determine if someone is eligible for the award, or the level of the award.

I recommend that: (1) Where there is evidence that an individual was the victim of unethical research practices IBCA should be authorised to make an unethical research practices award to that individual (2) When considering the evidence IBCA applies the wider definition of research explained above.

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[640] Letter from Dr Machin to Dr Kernoff 12 June 1985 WITN1696004

[641] Shelagh O'Shea Transcript 4 June 2019 pp6-8 INQY1000013

[642] Email from Luke O'Shea Phillips received by the Inquiry. Luke gave evidence with his mother on 4 June 2019. Email from Luke O'Shea-Phillips to the Infected Blood Inquiry 18 March 2025 LOSP0000001

[643] Cabinet Office Update on Unethical Research Awards January 2025 p1 WITN7754021

[644] The exchange was as follows:

"*Q. If that person has evidence that they were subjected to something which falls within the parameters of this award, wouldn't it be an awful lot quicker, bearing in mind that's your yardstick, you've told us, if they could go to IBCA and say: look. Look at my records.nLook at what this doctor said or did. Grant me that award?*

A. Again, I am more than happy to look at that. The yardstick I use is: does that cause undue delay in the generality of the scheme?"

Nick Thomas-Symonds Transcript 7 May 2025 pp169-170 INQY1000283

The amount of the award

Significant submissions have been made to the Inquiry that the level at which the amount of the award for unethical research has been set is too low.[645]

Gary Webster told the Inquiry:

> "*taking Treloar's, most boys went there for six, eight, ten years. Their experimentation and research wasn't a one-off. It happened daily, weekly for that period of time. Other haemophiliacs through the United Kingdom also suffered this, maybe not to the same extent, and I think the insult, and that's what it is, of £10,000 or £15,000 for that action they did to us is disgraceful … they really need to look at the tariff on that.*"[646]

Nick Thomas-Symonds said in his evidence that:

> "*Well, on this firstly let there be no doubt as to the unethical research that victims are subject to is a disgrace and an absolute stain on our country, frankly. So let there be no doubt or ambiguity about that. In terms of the amounts, what I accepted from Sir Robert Francis were obviously not those figures in isolation with nothing else. What I accepted were recommendations about uplift and uplift to the autonomy award. So say, for example, take the mid-point of around £50,000 on the autonomy -- I stand to be corrected on the figures but that's the figure I have in my head, clearly the 10,000 in respect of the unethical research that isn't Treloar's would be an uplift to that. The 15,000 would then be an uplift to that if it's in relation to someone who was at Treloar's. Now, I accepted those uplifts as they were put to me and they were recommended to me. What I didn't do was -- and I don't think it would be wise -- proportionate or reasonable for me to start inserting arbitrary figures instead, but I certainly accepted them as an uplift to the autonomy award in the very awful circumstances that people find themselves in.*
>
> *Q. And you will understand I know, minister, that arbitrary is exactly what people think of it; arbitrary and tokenistic?*
>
> *A: Of course I understand.*"[647]

An essential difficulty in setting monetary tariffs to compensate for wrongs is that it cannot turn back the clock to restore life as it would have been if those wrongs had never happened. Monetary compensation for a personal injury or affront cannot compensate like for like. Any sum thought appropriate will always be arbitrary, in the sense it cannot be calculated

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[645] Thompsons Solicitors for their clients describe the award as "*derisory and tokenistic*". Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) 23 May 2025 paras 2.51-2.57 SUBS0000084, Written Submissions made on behalf of the core participants represented by Collins Solicitors 23 May 2025 paras 56-58 SUBS0000092, Written Submissions on Compensation and IBCA on behalf of the Haemophilia Society 23 May 2025 para 7.19 SUBS0000087

[646] Gary Webster Transcript 7 May 2025 pp40-41 INQY1000283

[647] Nick Thomas-Symonds Transcript 7 May 2025 pp168-169 INQY1000283

precisely. The best guide is (1) to be clear what the award is meant to compensate; and (2) to adopt what in the judgment of the person setting the tariff would accord most closely with the general public's sense of justice.[648]

When the request for feedback was made in December 2024 in relation to unethical research, it looked just at the date range and the centres. There was thus little or no opportunity for people involved in it to make representations expressing their sense of concern (and outrage) regarding the amount.

In the light of these matters, I recommend that the Minister look again at the question of what the appropriate sum for this award should be. In identifying points (1) and (2) above he might wish to consider the submissions from the Haemophilia Society. They point out that the Government Update on the Infected Blood Compensation Scheme in 2025 gives the answer to "what is the core award meant to compensate"? It says that the present scheme "*recognises 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 Haemophilia Society points out (correctly) that these words suggest a narrower scope than that identified in the Second Interim Report of the Inquiry:

> "*It should include sums for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent, lack of sufficient information about the risks of treatment, and about diagnosis, treatment and testing, or being the subject of research without their informed consent. It should include the effects of lack of candour, and inadequate responses by authority.*"[649]

The March 2025 update suggests that the autonomy award as it presently is does not include a basic sum for being the subject of research without informed consent, or (for that matter) being treated without informed consent. The Regulations themselves give the two examples used in the Update (loss of marriage/partnership prospects, and loss of opportunity to have children) and add a third: "*impact on that person of attacks on that person's home as a*

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[648] Before the Second World War, many more claims for compensation brought before the courts were heard by a jury. The jury award was then the best test of what accorded with the general public sense of justice and fairness. There could be appeals if the figure was manifestly too low or too high, but experience suggested this was uncommon. However, though this has guided awards in the common law courts ever since by providing a rough precedent, there was still considerable room for debate about the figures which were appropriate. Now that court awards are very rarely if ever made by juries, but by judges, who themselves may differ as to the precise amount, it has been possible to set out guidelines for compensation which are based not on what the authors of the guidelines would personally award, but on a study to identify the range of awards which courts typically award for similar injuries. There remains scope for variation. However, the circumstances revealed by the Inquiry Report in May 2024 are unique and unprecedented, and thus the process of setting an appropriate figure more difficult. The best guide remains what would best accord with the public sense of justice. It should be easier to identify sums which are manifestly too low, or manifestly too high, than it is to agree on an exact figure.

[649] Written Submissions on Compensation and IBCA on behalf of the Haemophilia Society 23 May 2025 para 7.19 SUBS0000087, Infected Blood Compensation Scheme Summary February 2025 p13 RLIT0002481, Infected Blood Inquiry Second Interim Report 5 April 2023 p42 INQY0000453

consequence of the infection."[650] Thus in both the Regulations and Update there is nothing said to the effect that the core award covers unethical research.

I also recommend that: The Minister consider whether the £10,000 (£15,000 for Treloar's pupils) should in justice be increased and further decides what sum he considers accords most closely with the general public's sense of justice and fairness in respect of an individual being subject of research without informed consent.

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[650] Regulation 18(1) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p20 RLIT0002944

7 People affected

People affected severely

The 2025 Regulations make limited provision for a supplemental award for affected people: a supplemental award is only available to bereaved affected people who were financially dependent on an eligible infected person at the time of the latter's death. If eligible, they may be entitled to £5,561 per annum from the point of death to the estimated healthy life expectancy of the deceased (or £2,780.50 per annum for years where the infected person would have been 66 or older).[651]

The evidence which the Inquiry received from people infected and affected makes clear that there were partners, parents, children and siblings who suffered serious (and sometimes lifelong) psychological trauma, with some developing psychiatric disorders such as depression and PTSD. Many took on significant caring responsibilities, with adverse impacts on health, education and careers. The scheme as currently formulated does not provide a route for compensation for such harms.

A number of statements, submissions and other communications which the Inquiry has received suggest that a supplementary route should be open to affected people to reflect the impact on their physical and mental health, employment and education.

Tainted Blood – Affected Siblings and Children is a group of 440 bereaved family members who describe the complex trauma, educational harm and lost employment and earning potential they have experienced:

> "*Many of us suffered lifelong harm that affected our education, employment, and mental health – some entering abusive relationships or becoming distrustful of authority as a direct result of childhood trauma … In many cases bereaved parents developed serious mental health issues or addictions, leaving children without the stability to thrive … Many siblings and children lost employment or earning potential due to the long-term trauma or caregiving roles … adult lives were shaped by emotional instability, mental illness, or the inability to function consistently in the workforce.*"[652]

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[651] Regulations 56-58 of the Infected Blood Compensation Scheme Regulations 2025 pp62-64 RLIT0002944

[652] Letter from Tainted Blood – Affected Siblings and Children to the Paymaster General 12 May 2025 RNEW0000002. The letter contained the group's proposals and the Paymaster General responded: "*The outline set out in the letter addressed to me from Tainted Blood Siblings and Children is incredibly valuable and something I will keep in mind as I consider* [a tailored supplementary route for people affected] *further. It is useful to see what the community envisages for this potential supplementary route.*" Letter from the Paymaster General to Tainted Blood – Affected Siblings and Children 13 June 2025 p2 RNEW0000001

Janet Stuart, founder of HaemAffected, states:

> "*Despite the plethora of evidence available, ministers and staff alike continue to disregard the impact to our life outcomes, opportunities, attachment difficulties, and mental health, which have been marred by the disabling nature of our siblings' conditions, intensive parental caring responsibilities, HIV/Aids campaign and stigma of the 1980s, complex trauma, in a lot of cases from birth, bereavement and loss of relationship.*"[653]

Andrew Evans explained that one of the aspects of the compensation scheme people feel strongly about is:

> "*A lack of access to the supplementary route for the affected who have suffered through their own financial loss, either through giving up work to become a carer, or through the impact of mental health problems caused by their loved one's infection.*"[654]

The submissions on behalf of the core participants represented by Collins Solicitors explain:

> "*The rationale of a supplementary route for the infected was to compensate the exceptional, which is not covered by the 'normal' range of suffering. The same rationale should apply to the affected. If they too have suffered additional experiences outside the 'normal' range, they should receive additional recompense … especially where educational, occupational and psychological aspects have been adversely affected beyond the 'normal' anticipated experiences covered by the core award.*"[655]

James Quinault explained why a supplementary route for people affected had not been part of the initial design:

> "*The difficulty with -- the issue with a supplementary route of the affected and this was the reason why it was not part of the Government's original proposals is that that would have to cover a very wide group of things. It's difficult to see a way of setting tariffs for all of those eventualities, the alternative is something with a great deal of discretion in it and although discretion would allow IBCA to consider the circumstances in front of it, it does have downside in terms of possible delay and so that is why the Government originally considered whether a supplementary was appropriate for affected, and decided not.*"[656]

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[653] Written Statement of Janet Stuart para 18 WITN5241003

[654] Andrew Evans Transcript 7 May 2025 p23 INQY1000283

[655] Written Submissions on behalf of the core participants represented by Collins Solicitors paras 49 and 51 SUBS0000092. See also Written Submissions on behalf of the care participants represented by Thompsons Solicitors (Scotland) para 2.50 SUBS0000084, Written Submissions on behalf of the core participants represented by Leigh Day para 52 SUBS0000088

[656] James Quinault Transcript 8 May 2025 pp137-138 INQY1000284

Nick Thomas-Symonds told the Inquiry that he would be willing to look at the question of creating a supplementary route for the affected, acknowledging "*the extraordinarily powerful testimony from affected people who lost loved ones whose lives have been completely and utterly turned upside down and devastated by what has happened.*"[657]

I agree with James Quinault that a supplementary route is likely to involve some discretion. I assess however that it should be well within the capabilities of IBCA to exercise such a discretion in relation to exceptional circumstances without causing significant delay to the process as a whole. I note too that there is potentially a route which does not involve any more discretion than is currently exercised, and that is to open up applications for a supplemental award for severe psychological harm to people affected.

I recommend that: The Minister give consideration to there being a supplementary route for people affected. This could include opening the supplemental award for severe psychological harm to people affected. He should involve parents, children, siblings, partners and carers, and their legal representatives if wished, in this consideration.

Deceased affected

The current position under the compensation scheme is that the compensation of an eligible affected person does not pass to their estate if they die,[658] unless they die after accepting an offer of compensation but before the full balance of compensation has been paid. It is only fair to observe that the fact that the affected person's claim does not become part of their estate reflects the view I expressed in the Inquiry's Second Interim Report in April 2023.[659] It is also only fair to observe that this differed from the view expressed by Sir Robert Francis in his Compensation Study in 2022 and, as he told the Inquiry when he gave evidence in May 2025, "*my view as expressed when I initially reported on that has not changed.*"[660]

Many of those who have written to or provided statements or submissions to the Inquiry have expressed their concerns about this position, in particular in circumstances where IBCA has not yet even begun making compensation payments to people affected and the process of doing so may take several years. For example:

> "*The length of time of the roll-out of compensation is leaving people in fear that they won't live long enough to see justice. For some, that fear has already been realised, having been invited to claim but dying shortly afterwards. In the case of*

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[657] Nick Thomas-Symonds Transcript 7 May 2025 p148 INQY1000283

[658] Regulation 4(1) states "*a person is an eligible affected person if they are not deceased, and …*" Regulation 4(1) of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p9 RLIT0002944

[659] Infected Blood Inquiry Second Interim Report 5 April 2023 p36 INQY0000453. The Minister placed some weight on the Inquiry's recommendation in his oral evidence. Nick Thomas-Symonds Transcript 7 May 2025 pp143-144 INQY1000283

[660] Sir Robert Francis Transcript 8 May 2025 p94 INQY1000284

> *ill or elderly affected, they know that their claim dies with them, and that this is justice lost forever.*"[661]
>
> "*There's this idea that if you are an affected victim and you don't get into the process, you've no rights. Your rights are wiped out. You didn't exist. I know many people who have complained to me in Northern Ireland about that anxiety and many of the older generation have just accepted, sadly, that they're not going to receive any recognition, because that's what it is, for what they have gone through, as parents primarily.*"[662]
>
> "*The way it's going, people will not get justice. People will not get their compensation and a lot of claims will die with them. It won't get passed on to families. Most of the families and parents of Treloar boys are very elderly now. If they have got to wait another four years, who knows what's going to happen.*"[663]
>
> "*I know people in their 80s who are widows who are in dire straits who still have mortgages. There are widows who have died who will now get no compensation, because of this ruling that they've made that the affected, if they die before their claim is met, then they will get nothing, and I think this is disgraceful.*"[664]
>
> "*For many affected people, some who are elderly and ill themselves, like widows/ widowers, parents of deceased children, they should be allowed to have the compensation they are due in their own right to be paid to their estates should they themselves die before finalising their compensation. Under the existing regulations their compensation will die with them should they die before their compensation is finalised. This is not natural justice for such an unprecedented disaster. Many such people are dying and the rate of death will only increase month by month.*"[665]
>
> "*If our parents had been compensated when they were harmed, many families might have avoided collapse. The Inquiry's suggestion that the circle of affected individuals must not be 'drawn too wide' does not reflect the true intergenerational impact of this disaster.*"[666]

In the written submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland), it is suggested that this gives rise to a "*clear injustice which must be remedied*", in light of "*the delays which have been experienced and the reasonable*

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[661] Andrew Evans Transcript 7 May 2025 pp24-25 INQY1000283

[662] Nigel Hamilton Transcript 7 May 2025 p35 INQY1000283

[663] Gary Webster Transcript 7 May 2025 p39 INQY1000283

[664] Mary Grindley Transcript 7 May 2025 p43 INQY1000283

[665] Caz Challis Transcript 7 May 2025 pp82-83 INQY1000283. See also the view expressed by Nicola Leahey (communicated on her behalf by Samantha May): "*I want the affected person's claims not to die with them if not awarded and accepted. We are an ageing population and that affected person may have had to give up work and therefore the money lost would have been part of their estate.*" Transcript 7 May 2025 p100 INQY1000283

[666] Letter from Tainted Blood – Affected Siblings and Children to the Paymaster General 12 May 2025 RNEW0000002.

anticipation on the part of the Inquiry at the time [its original recommendation] *was made that the compensation scheme would be up and running long before now*":

> "*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 … mean that it could not have been anticipated that this cut-off would result in the injustice which it now inevitably will.*"[667]

The written submissions on behalf of the core participants represented by Watkins & Gunn suggest that:

> "*The regulations should be amended so that where an affected partner was still alive as at 31 March 2025, their claim will pass to their estate. This draws a reasonable line between the Inquiry's conclusion that including the estates of the affected drew the circle too wide, and the unfairness caused by the delay in the processing of claims. The requirement that an affected person must have accepted an award before they die in order for the compensation to be payable to their estate results in conspicuous unfairness arising from (i) the delay to date in the establishment of the compensation scheme, and (ii) the indication that the 'bulk' of affected persons will receive compensation by 2029.*"[668]

Commentary

The point which Thompsons Solicitors (Scotland) make, as set out above, is a valid one. My recommendation that the claims of a person affected should not form part of their estate was made at a time when the Inquiry did not anticipate the serious delays there have been in delivering compensation. The effect of IBCA's approach of dealing with people affected after people infected means that, in their case, yet further time will pass before they will receive compensation.[669] If their claims had been processed with greater speed, the money paid to them in compensation would form part of their resources, and if they were then to die, their estate. The result in a number of cases will have been that people who had every expectation of receiving an award, and being able to pass at least some of it on to their own loved ones, have lost out as a consequence of the length of time that compensation is taking.

It has been acknowledged that where an affected person's claim has resulted in an offer and that has been accepted, though not yet paid, it is a debt due to the person and thus will form part of their estate. That is a true reflection of the legal position. It is problematic because it means that if IBCA chooses to deal with claim A before turning to claim B, when both die

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[667] Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) paras 2.58-2.60 SUBS0000084

[668] Written submissions on behalf of the core participants represented by Watkins & Gunn para 4 SUBS0000091. This is echoed by Leigh Day: "*compensation that an affected person would be entitled to in the event of an application should transfer to their estate after their death. At the very least, people currently alive but whose claims cannot be processed yet should remain eligible.*" Written submissions on behalf of the core participants represented by Leigh Day para 53 SUBS0000088

[669] Bereaved partners may have received an interim payment but all other people who were affected by the infection of someone near to them will have received nothing as yet.

shortly after, it may effectively be choosing whose claim shall be heritable. It is problematic, too, that by not being in a position to pay an otherwise valid claim because of delays for which it is responsible, the state is seen as receiving a windfall. I have come to the view that more can be done to remedy the disadvantage caused by delay, whilst maintaining more generally the principle that the circle of people benefitting from compensation should not be drawn too widely.

The Cabinet Office has told the Inquiry that payments to people affected who have come forward should have been made by the end of 2029.[670] As people affected wait to have their compensation considered, it would ameliorate some of the distress for those who are older and not in good health to know that even if they themselves do not live to see justice, their compensation will not die with them. The design of the scheme will have allowed for the claims of the living affected to be satisfied and so permitting claims from the recently deceased affected should cause no unanticipated additional expense.

In order to meet the problem of delay which has arisen, the extent of which had not been foreseen at the time of the recommendations in the Second Interim Report:

I recommend that: The Regulations be amended such that where someone who would be an eligible affected person dies between 21 May 2024 and 31 December 2029, their claim does not die with them but becomes part of their estate.

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[670] Third Written Statement of James Quinault para 71 WITN7755006. See *3 Operation of the Compensation Scheme*.

8 Bereavement after 31 March 2025

Under the support schemes, a bereaved partner was entitled to receive 75% of the annual support payments that were being received by their infected partner.[671] Those whose partners died on or before 31 March 2025 will continue to be eligible for and to receive these payments.

However, under the compensation scheme any person whose partner dies on or after 1 April 2025 will not be entitled to such payments. The payments from the support schemes will simply stop on their partner's death.

This has, unsurprisingly, caused substantial concern and anxiety:

> "*Given that I had been receiving SIBBS 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 after 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.*"[672]
>
> "*The Government has also recently announced that if an infected person passes away after 31 March 2025, their bereaved partner will not receive support payments. Again, this has caused great upset and anxiety.*"[673]
>
> "*The spouses/partners of any victim who dies after the 31st of March 2025, will also be excluded from the Support Scheme mechanism. This policy generates a discrimination of existing beneficiaries and does nothing to recognise the spousal rights or damage done to the pension rights of spouses and the impact of the loss of support payments of their infected loved one. The government has effectively disregarded what is an established right to support payments for spouses and partners. This means all bereaved of those that die between now and a compensation payment will be left grieving and without any financial support …*"[674]

Andrew Evans, in his oral evidence to the Inquiry on 7 May 2025, referred to "*The removal of support payments to any partner bereaved after 31 March 2025, leaving those infected seeing themselves as worthless and igniting fears of leaving partners destitute.*"[675]

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[671] Under the schemes, upon the death of a registered beneficiary, the surviving partner could receive the equivalent regular payment for one year at 100% and for subsequent years payments at a rate of 75% of the beneficiary payment.

[672] Fourth Written Statement of William Wright para 15 WITN2287087

[673] Second Written Statement of the Scottish Infected Blood Forum para 25 WITN7165016

[674] Scottish Infected Blood Forum Carers Survey p6 SUBS0000095

[675] Andrew Evans Transcript 7 May 2025 p24 INQY1000283

Patrick McGuire, of Thompsons (Scotland), explains that this issue has been raised repeatedly, noting that it has "*caused great anxiety, and has robbed infected people of the reassurance of knowing that their partners would be financially secure in the event of their death.*"[676]

On 26 May 2025 Tainted Blood Widows and Tainted Blood issued a statement "*with deep sadness and rage*":

> "*We have recently been informed of yet further deaths within our contaminated blood community which, due to a backward move by the British Government, leaves their bereaved spouses and partners facing a potentially catastrophic financial loss to their household income, a loss which may lead to destitution and homelessness at a time of unimaginable trauma and grief.*
>
> *As a direct result of the Government's decision, recent deaths since the 31st March 2025, have potentially placed partners in the same devastating and financially ruinous situation suffered by others before them during previous decades, as evidenced in harrowing testimony to the Inquiry. It is clear to us that they have learned nothing from that and continue to cause trauma to people already ravaged by decades of loss, grief and ill-health.*"[677]

The rationale for removing the provision for a 75% payment to bereaved partners, after the 31 March 2025, appears to be that bereaved partners will be eligible for compensation as people affected. Thus, James Quinault explains:

> "*From 31 March 2025, bereaved partners are now eligible for compensation in their own right under the Scheme. While the Government will not take away these support scheme payments from existing beneficiaries, it is not proposing to extend them to new claimants, as the Compensation Scheme now exists.*
>
> *To recognise financial dependency the Scheme will pay compensation for financial loss to a bereaved partner up to the expected healthy life expectancy of the partner who became infected.*
>
> *Infected persons who pass away after 31 March 2025 can, through their estate, make provision for a partner from their own compensation if they wish.*
>
> *Bereaved partners are also eligible for compensation under the Scheme in their own right as affected persons.*"[678]

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[676] Written Statement of Patrick McGuire para 50 WITN7760001. See also the Written Statement of John Dearden on behalf of Haemophilia Scotland, commenting on the assurance that no one would be financially worse off as a result of the compensation scheme: "*the widows/partners of an infected person who dies after 1st April 2025 will be significantly worse off than if the infected person had died at an earlier date.*" Written Statement of John Dearden on behalf of Haemophilia Scotland para 13 WITN7754001

[677] Tainted Blood Widows and Tainted Blood Statement 26 May 2025 p1 ANDE0000003

[678] Second Written Statement of James Quinault paras 211-214 WITN7755003

And in his oral evidence James Quinault said the reason why the Government thought it "*acceptable to end that entitlement*" is that "*there is now a compensation scheme which pays compensation to estates but also to bereaved partners in their own right.*"[679]

However, there are difficulties with this rationale because:

- It creates an arbitrary difference between the entitlements of bereaved partners: all such partners will be affected and entitled to compensation under the scheme, but only those whose partners died on or before 31 March 2025 will have the option of receiving ongoing support payments.
- It does not recognise the serious adverse consequences of the delay in rolling out compensation – the scheme is not yet paying compensation in respect of the deceased infected, which means that a bereaved partner who would have received 75% of the deceased's support payments on and before 31 March 2025 receives nothing yet. They have to wait.
- Bereaved partners are indeed entitled to compensation as affected persons – but the scheme has not yet begun dealing with the claims of people who were affected. They have to wait.
- It follows that the two potential sources of financial support from compensation scheme payments will not be available for a while – potentially for a substantial period of time, given the current and anticipated state of progress. A future entitlement to compensation which may not be received until 2029 ignores the difficulties that a newly bereaved partner may find themselves in during the interim. They will have lost the support that the scheme would otherwise have given them simply because of the delay between the date of death and the date of payment of compensation under the scheme. At a time when they will be most vulnerable they will have the least resource available to help.

Nick Thomas-Symonds was asked about this issue:

> "*Q. … if an infected person dies after 31 March, their widow or widower will not be entitled to the continuation of the support scheme payments that these families may have depended on for years and which they had previously understood to be for life. So somebody who dies on 30 March, their widow or widower will continue to get those payments, someone who dies on 2 April, their widow or widower will not. Now it's no answer, is it, to say: well, you'll finally get compensation when your claim is assessed in 2029 because there are going to be people in profound financial difficulty, anxiety, distress because those support payments have been cut off as at that date. Will the Government look at that again?*

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[679] James Quinault Transcript 8 May 2025 p146 INQY1000284

> *A. Well, certainly the point about the gap I am going to suggest is obviously an issue of concern, but let me just explain: the point of the date is that within the scheme you do need past loss and you need future loss and there does need to be a date that is the cut-off between those things for the integrity of the scheme. But to the broader point that if it was a consequence and there are people who are in difficulty for the reason that you suggest, then obviously that is something that we would be willing to go back and look at.*"[680]

I accept that, as he said, a date is needed to separate past loss from future loss and the Regulations provide this.

This does not however address the immediate problems for a newly bereaved partner. They will suddenly face a steep, sharp drop in income which they would not have done if the support schemes had continued – and have to wait until the compensation claim is dealt with, which on present timescales may not be until 2029. The drop in income lasts until compensation is paid. It is the gap in income, necessary for support, which needs to be covered if real hardship is to be avoided – and it is in large part a consequence of the delays in processing claims.

In the course of his evidence during the panel session on 7 May, one of Andrew Evans' recommendations was to "*Immediately reinstate support payments to bereaved partners after 31 March 2025 until such time as they receive compensation and have the continuing payments as an option in their compensation package.*"[681] I do not think I can improve on his formulation, except that in place of "*immediately*" should be "*as soon as possible*", recognising that an amendment to the Regulations may be needed.

I recommend that: The IBSS cut-off date of 31 March 2025 be reviewed, that the scheme should as soon as possible reinstate support payments to partners bereaved after 31 March 2025 until such time as they receive compensation and that they should have a continuation of those payments as an option in their compensation package.

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[680] Nick Thomas-Symonds Transcript 7 May 2025 pp145-146 INQY1000283

[681] Andrew Evans Transcript 7 May 2025 p85 INQY1000283

9 Recommendations

9.1 Approach

In principle, what matters in the public interest for the future of the scheme, its acceptability for those it seeks to compensate, and what best serves its function of providing redress for serious infections and their disastrous consequences, is:

- Speed of delivery
- Letting individuals know with as much certainty as possible when their application is likely to be dealt with (thereby easing anxieties of not knowing and concerns that they may never receive a payment in their lifetime)
- Ensuring transparency of process
- Meaningfully involving people infected and affected throughout
- Involving lawyers where individuals wish it, and making use of the huge experience many of those have accumulated over the years
- Ensuring adequate psychological support through the four national health services
- Adjusting the legislative provisions to ensure greater fairness, in particular by resolving anomalies and addressing circumstances which have not been properly taken into account thus far
- Remedying the consequences of the fact that it will take much longer than was to be expected to deliver compensation to many people who are entitled to it

These bullet points reflect the concerns so forcefully (and increasingly) expressed to the Inquiry over the last nine months. Few could argue against these headline aims. However, acceptance of them should lead to action. Without sufficient action in respect of each, trust in the scheme, in IBCA, and in the Government which oversees them is unlikely to recover.

Recommendations for the actions which are needed come in two parts in this chapter.

The first part concerns the speed and fairness with which the compensation scheme is being operated. It deals with whether the processes adopted by IBCA can and should be improved, and how. [682]

The second part deals with concerns that have been expressed about provisions in the scheme for compensation.[683] This centrally raises matters which are for the Minister, the Government, and Parliament to address. Nick Thomas-Symonds, rightly, has been concerned to increase the speed of delivery. His oral evidence to the Inquiry is clear that he

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[682] See Chapters 9.2 *Speed and fairness* and 9.3 *Transparency and involvement*.

[683] See Chapter 9.4 *Adjusting the provisions of the scheme.*

is open to justifiable changes provided they do not significantly prejudice this. Wholesale revision of the scheme would cause significant delay, and is not now a realistic possibility.[684] The proposed alterations which I recommend in this Additional Report respect the Minister's evidence that he is open to changes being made to the legislative scheme if they are unlikely to cause further undue delay.[685] I am confident that these recommendations should not cause delay.

9.2 Speed and fairness

By far the greatest volume of complaints and concerns prior to the hearings in May related to the speed of delivery of compensation. When IBCA started to process compensation claims it decided on an approach that involved "starting slow" before building up speed. However much the aim may have been to ensure a faster speed in the long term, by discovering and ironing out glitches in the process at an early stage, the consequence was that progress was indeed slow. It was far too slow in the eyes of many observers. Many have expressed anger and distress.

This is not the time, though, to dwell with regret on the past, but instead to take the opportunity to concentrate constructively on the future.

IBCA says that it intended that the process should gather speed after its slow beginning – and it has now begun to do that. In addition IBCA and the Government are taking decisions to speed up the process.[686] However, the rate at which claims are successfully processed can and should be increased further.

The recommendations in this chapter aim to increase speed of delivery overall and fairness by:

(a) allowing individuals to apply without having to wait to be asked so that IBCA understands the scale of its work and can plan accordingly

(b) enabling individuals to be more proactive when starting the application process, if they wish to be, and thus respecting their autonomy

(c) making better use of lawyers and third parties to assist IBCA – the provision of compensation should be seen as a system in which IBCA has the deciding role in accordance with the Regulations, but need not itself perform every preparatory step

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[684] The submissions from Thompsons Solicitors (Scotland) did use those words and they have written to the Inquiry to clarify that they did not intend in their submission to advocate a new scheme as such: their clients wish meaningful reform within the existing framework, not its abandonment. Letter from Thompsons Solicitors (Scotland) to the Infected Blood Inquiry 20 June 2025 THOM0000004, Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 2.39 SUBS0000084

[685] Nick Thomas-Symonds told the Inquiry: "*my test for this is always the same in terms of the decisions I have faced as minister since last July and that is that I don't do things that would cause even greater delay for justice. That is always the test that I place on these matters.*" Nick Thomas-Symonds Transcript 7 July 2025 p148 INQY1000283, Submissions on behalf of the Cabinet Office para 5 SUBS0000082

[686] As described in *Operation of the Compensation Scheme*.

towards that decision, such as obtaining evidence or documentation where others may be well placed to provide it.

The proposed changes also aim to provide greater certainty to individuals about the length of time they are likely to have to wait before their compensation is finally paid.

Registration

The scheme should be opened to registration to everyone who may be eligible.[687] Anyone who wishes to establish their entitlement should be able to register.

The reasons for this are fourfold.

First, unless and until everyone infected and affected is entitled to register their wish to be paid compensation, IBCA can have no proper idea how many claims they may have to consider. Without an accurate sense of how many claims are being made it is difficult to see how IBCA can be confident of any estimate it makes as to when such claims will be paid. Knowing how many claims are in the pipeline allows for manpower planning, checking that the rate of claims is on target, and deciding what needs to be budgeted for. In short, it enables speed to be better planned for.

Second, without a system of registration allowing for sufficient up-to-date details of individual applicants to be provided, priority cannot be given to people who most need it.

Third, it is what the natural reading of the legislation suggests was the intention of Parliament when it approved the regulations laid by the Minister.[688] It corresponds with the expectation

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[687] People infected (including those never previously compensated), the deceased infected and people affected.

[688] See in particular Regulations 14 and 65. Regulation 14 of the 2025 Regulations speaks of "*an application*". It provides that the application is to be in writing. It sets out dates before which an application must be made (a provision which makes little sense if an application is only to be permitted if and when IBCA calls for it): the provision seems to regard the potential applicant as the person who has to meet the time limits, not that the scheme itself has a theoretical right to determine whether they are met or not by being too late in calling on would be applicants to make a claim (it should be added that this is not a suggestion that IBCA ever would do this – the point is merely that the Regulations do not appear to contemplate that the right to start a claim is effectively to be exercised by IBCA and not by an applicant). Regulation 14 further provides that if a person making the claim intends that a care award in their case be paid ("*assigned*") to an affected person, they must give details of that person in the application – again, a provision which shows that the natural understanding of "*application*" is a document compiled by a person wishing to be paid compensation ("*the applicant*") rather than a request from IBCA to begin a claim. The intention of the applicant as to assignment would be unknown unless and until they made an application. Regulation 14 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) pp17-18 RLIT0002944. Chapter 2 of Part 6 of the Regulations provides further provisions about making an application. Regulation 65, within that Chapter, reads:

"*(1) An application must be–*

(a) *made in writing to the IBCA by the relevant person,*

(b) *In a form approved by the IBCA, and*

(c) *Signed by the relevant person.*

(2) An application is to be treated as having been made on the date on which it is received by the IBCA." Regulation 65 of the Infected Blood Compensation Scheme Regulations 2025 (Statutory Instrument 2025 No. 404) p69 RLIT0002944. This too is strongly supportive of the view that Parliament expected the process to start with an application.

that a person making an application will have control of when it is begun, rather than having to wait to be asked to make a claim and wonder if this week will be the week or when the service might be opened up to others.[689]

Fourth, closing submissions from core participants have called for registration to begin forthwith.[690]

I recommend that: The scheme be opened to registration to everyone who may be eligible.

Registration and Application Forms

It follows from my first recommendation that there should be forms (devised by IBCA and accessible on IBCA's website) for people both to register and apply. Some people may choose to complete the application form themselves or with the legal support IBCA funds, and others may choose to wait until a claim manager is ready to assist them. The application form should enable people to provide the evidence in support of their claim as well as a calculation of the compensation for people who wish to include that, prepared by themselves or their lawyer.

This builds on the submissions made on behalf of the clients represented by Milners Solicitors that IBCA "*accept pre-prepared declaration forms supported by evidence bundles*" both from people legally represented and unrepresented if they wish to provide it. This has

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[689] It is offensive for people to be told that they are to be given an entitlement but told that they cannot apply for it: that they may be entitled to compensation, but that they are not allowed to apply for it until they are asked, especially if it is unclear why **they** in particular should have to wait, and without knowing how long they are likely to have to wait. The "*relevant date*" for the purposes of the scheme is defined as the date of application. Thus it matters when that is. For instance, the deeming provision in cases of Hepatitis which sets out the levels of severity of the infection works backwards from the date of application: it makes little sense and works to the detriment of the applicant that that date should be determined by when the scheme calls for the applicant to begin the process rather than the applicant being in control of the start of the process.

[690] The Haemophilia Society says "*IBCA should immediately open registration lists for: The affected; Bereaved partners; Those infected not currently registered on a scheme … Loved ones lost before the schemes were in operation.*" Written Submissions on behalf of the Haemophilia Society para 7.6 SUBS0000087. Watkins & Gunn say: "*All eligible persons should be able to register for the scheme*". Written Submissions on behalf of the core participants represented by Watkins & Gunn para 8 SUBS0000091. Thompsons Solicitors (Scotland) say: "*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.*" Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 3.2(a) SUBS0000084. Leigh Day say: "*A registration or waiting list should be established for all currently unregistered groups. This would enable a clearer understanding of the number of individuals within these cohorts, thereby informing the scale and type of resources required to support them effectively.*" Written Submissions on behalf of the core participants represented by Leigh Day para 33 SUBS0000088. Saunders Law submit that IBCA should "*immediately i) Open applications for people alive, infected and not registered with any scheme, for example those with mono-infection of chronic HBV. ii) Open registrations for affected. This will require details of the person they are related to and details of their oldest beneficiary and any diagnosis of 12 months to live among beneficiaries. They should be paid at the same time as the person to speed up the process.*" Written Submissions on behalf of the core participants represented by Saunders Law para 14 SUBS0000089

"*wholehearted*" endorsement from Collins Solicitors on behalf of the large number of clients they represent.[691] Milners Solicitors explain their experience that:

> "*where documents are readily available, an evidence pack can be produced ahead of the initial IBCA call. The cumulative effect of all this is that the length of time from claim commencement to declaration form signature has been, in some cases at least, heavily truncated. The result is that the person making their claim is happy that their claims proceeds extremely quickly and that the claim manager should have more time to progress more claims at once.*"[692]

IBCA do not encourage this on their website, though David Foley said they welcome people providing evidence:

> "*when a person begins their claim, they absolutely can send anything and everything that they would like to send to us. So that is accepted and would be well received.*"[693]

David Foley was asked if IBCA saw any disadvantages to a system in which people have the option to provide IBCA with a completed application form with/without calculation of compensation that either they or a funded legal representative has completed. He stated:

> "*If individuals already have all the necessary information, that is welcome and we can certainly use this to speed up the information and evidence gathering stages of the claim journey. In many cases, we do see this already when claims are started. As a result, we are already exploring how we can provide the option to move straight to the declaration stage for individuals where we hold all the necessary information and we will explore how we can continue to work with claimants and legal representatives to support the provision of the information that they hold in this process.*"[694]

I recommend that, in effect, the forms should allow people to register and apply with three options – registration with a minimum of information, a fuller application form (with a pre-prepared evidence bundle if the individual so chooses) and the option for an individual or their lawyer to provide a calculation of the award considered due. People should also be able to register and later complete an application form and, if they wish, provide the calculation so they do not feel under pressure to provide everything at once.

Recognising that this could not be implemented on the day IBCA's Board considers it, as an intermediate step, IBCA should provide the option David Foley states they are already

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[691] Written Submissions on behalf of the core participants represented by Milners Solicitors para 121 SUBS0000086, Written Submissions on behalf of the core participants represented by Collins Solicitors para 7 SUBS0000092

[692] Written Submissions on behalf of the core participants represented by Milners Solicitors paras 118-119 SUBS0000086

[693] David Foley Transcript 8 May 2025 p59 INQY1000284

[694] Third Written Statement of David Foley paras 22-23 WITN7757011

exploring for individuals to move straight to the declaration stage for individuals providing all the necessary information.[695]

I recommend that: There be forms (devised by IBCA) for people to register and apply for a core award and the supplementary awards with/without the necessary evidence and with/without calculation of compensation, and as an intermediate step that IBCA provide the option to move straight to the declaration stage for individuals providing all the necessary information.

It is important that people are informed about the availability of legal support paid for by IBCA so that they are in a position to make informed decisions about the services they need, particularly when application forms become available and given the number of firms of solicitors online who are offering assistance with infected blood compensation claims on a "no win no fee basis". The chapter on *Operation of the Compensation Scheme* notes the willingness of the Solicitors Regulation Authority to remind solicitors of their obligations.

I recommend that: IBCA include a prominent reference to the availability of legal support paid by IBCA on all registration and application forms and in public information about the compensation scheme and that the Solicitors Regulation Authority remind solicitors of their obligations.

Triage

Three cohorts of applicants are readily identifiable: people who are living infected; people claiming on behalf of the estates of people who were infected and have died ("deceased infected"); and people who are affected.[696] In the case of each, the information given on the registration form would enable the application to be assigned to the relevant cohort. Each cohort should then be dealt with in an order of priority which ensures that the number of people who live long enough to receive some benefit from compensation is maximised, and that those who wait for consideration of their applications to be started understand why others are being dealt with first. The cohorts can be addressed contemporaneously with each other, once the system is in place. During the Inquiry hearings, IBCA has been able to state that it intends and expects to start assessing compensation before the end of 2025 for every living person who is registered with a support scheme as infected.[697] Nothing in these recommendations should hinder IBCA in achieving that aim.

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[695] As quoted above.

[696] IBCA has set out six groups, which broadly correspond (but also refine) these three, but which distinguish between people registered with support schemes and people who are unregistered. IBCA plans to build the claim service in stages, which are living infected people who are already registered with a support scheme, supplementary claims, registered estates, people who are affected and linked to a registered infected person or registered estate, people who are infected but not registered with a support scheme (unregistered infected), and personal representatives applying on behalf of an estate that is not registered with a support scheme and people who are affected and not linked to a registered claim. IBCA Community Update 10 February 2025 pp5-6 RLIT0002482

[697] David Foley Transcript 8 May 2025 p46 INQY1000284, IBCA Community Update 14 May 2025 pp3-4 RLIT0002970, Third Written Statement of David Foley para 40 WITN7757011

Which applications should be first to be considered? In the week following the hearings of 7 and 8 May, the Inquiry wrote to core participants inviting their submissions on whether applications should be dealt with in accordance with an order or priority. It proposed that they be ranked according to relevant factors which differed as between each of the three cohorts.

Most, but certainly not all, of the responses to this proposal have favoured such a system.[698] Though there has been discussion about some of the factors, there has been almost universal acceptance that those people who have been told that they have a year or less to live (and are willing to let this be known to IBCA) should be considered first. IBCA has adopted this approach for people infected who are registered with the schemes.[699]

It is right that this should be so, but there is no further system for deciding who, within any cohort, should be considered next. At the moment selection is random. It feels arbitrary. Leigh Day, on behalf of their clients, are clear that a prioritisation framework is necessary, but add that a prioritisation framework needs to be "*not only fair, transparent and well informed, but also sensitive to the diverse ways in which harm has been experienced. The process must avoid rigid assumptions and ensure that all claimants — including beneficiaries, the bereaved, and those living with long-term illness — are treated with dignity, consistency, and care.*"[700] This is plainly right, but it begs the question as to what factors should be used

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[698] "*Rather than random selection of victims prioritise by age in all cohorts.*" Submission by Families and Friends of Haemophilia NI p1 SUBS0000093. Leigh Day on behalf of their clients submit that in principle, clear prioritisation is necessary, and that IBCA should have the operational capacity to prioritise multiple strands of assessment simultaneously, adding "*In particular, it should be able to progress the testing and processing of the three key categories identified above, rather than sequentially.*" Though some of their clients were concerned that the Inquiry's proposals would place them at the back of the queue simply because of their age and the fact they had already received an interim payment, other participants whom they represented "*... welcomed the Inquiry's proposal, as a structured and transparent approach to prioritisation. They supported the creation of three parallel lists of claimants, scored according to relevant factors such as health status and age. They agreed that this method would allow for fairer outcomes, particularly in cases where individuals may be seriously ill but have not disclosed their condition. The proposal to update the lists regularly and notify applicants of their position — and any changes to it — was also seen as a positive step toward building trust in the process.*" Written Submissions on behalf of the core participants represented by Leigh Day para 24, paras 27-28 SUBS0000088. Milners Solicitors on behalf of their clients say "*Whilst there is a relatively broad consensus that people within the last year of their life ought to be brought forward to make their claim, beyond that we see very little consensus; this makes it extremely difficult to rank the factors for consideration.*" Written Submissions on behalf of the core participants represented by Milners Solicitors para 152 SUBS0000086. Thompsons Solicitors (Scotland), on behalf of their clients, recognise an inevitability about the need for some prioritisation, call for priority to those who have so far had no form of compensation or support payment "*at least to the point of registering them so that they can access interim payments*", and suggest a "*clearer priority for those who are elderly and/or in poor health*" adding that "*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).*" Written Submissions on behalf of the core participants represented by Thompsons Solicitors (Scotland) para 3.2b, para 3.2c SUBS0000084. Michael Imperato, representing the clients of Watkins and Gunn comments that many of his clients who are affected "*are elderly and poorly*" and "*afraid they will never see justice in the form of compensation*", thereby indicating a desire that they be prioritised. Written Submissions on behalf of the core participants represented by Watkins & Gunn para 8 SUBS0000091

[699] IBCA website *IBCA to prioritise claims for those who are nearing the end of their life* 14 April 2025 RLIT0002492

[700] Written Submissions on behalf of the core participants represented by Leigh Day paras 24, paras 27-28 and para 30 SUBS0000088

to determine priority, at least initially. It is not appropriate to expect people infected and affected to build a scheme from scratch, since each has an interest in their own entitlement under the scheme and it is difficult to defend placing them in the position in which advancing their interest in receiving compensation first may be seen by them as a divisive jumping of the queue, whilst not advancing their claim to avoid this would be self defeating. It follows that it should be for a third party, IBCA, to adopt a scheme of prioritisation which aims to maximise the number of people who live to receive some benefit from compensation. I recommend that IBCA consider adopting a scheme of prioritisation within each cohort which can be objectively applied and is easily understandable.

The principle of ensuring that as many people as possible receive some compensation in their lifetime means that those whose health is most seriously compromised or those who are elderly should have their applications processed before others: it also means that, after those, the claims of people who have never had interim support or compensation (including people infected with Hepatitis B and people infected with Hepatitis C after September 1991) should be prioritised over those who have had some.[701]

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[701] People infected with Hepatitis B and people infected with Hepatitis C after September 1991 have never received any form of financial support or compensation. They were not eligible for support from any of the Alliance House Organisations or from the national support schemes which replaced the Alliance House Organisations, even where it was accepted that they had been infected by blood or blood products. An example of this is what happened in relation to Caz Challis. The Skipton Fund was obliged to reject her application. EIBSS accepted that she was infected with Hepatitis C as a result of transfusions received in 1992-3, but it too had no power to compensate her. She said: "*I am almost 70 years old, and I have been fighting for inclusion since 2004 when I was rejected by the Skipton Fund because of the timing of my infection. We are living infected, yet we are denied all financial and psychological support, and our lives are ticking by fast. We've gone from the euphoria, hope, validation, vindication and relief of hearing Sir Brian deliver his final report in May 2024 to despair, anger and frustration, as nothing has changed for us. Several campaign groups are persistently advocating on behalf of the cut-off date cohort, yet their calls for change have so far fallen on deaf ears*." Written Statement of Carolyn Challis para 1, paras 4-5 WITN0622013. Paul Desmond of the Hepatitis B Positive Trust said: "*HBV victims feel that they are once again being forgotten … The failure to prioritise these patients means that many more of them will pass away prior to ever seeing any kind of justice for what happened to them*." Written Statement of Paul Desmond para 35 WITN0479044 The document "*Infected Blood Compensation: Getting It Right*", put together by charities, groups and individuals concerned with infected blood compensation, observes that: "*It has been a long-standing omission for HBV infectees to be ignored, while their suffering at the hands of NHS treatments, many of which were not even necessary and none of which were consensually administered, is commensurate with the damages to the HCV group of sufferers.*" Infected Blood Compensation: Getting it Right November 2024 pp12-13 WITN7165021 Mark Lawler, whose late mother was infected with Hepatitis B following a blood transfusion in 1977, has recently written to the Inquiry to state that: "*The Hepatitis B community remains severely underserved and demonstrably ignored within the ongoing compensation framework. As a peer supporter, I can personally attest to the significant and detrimental impact this sustained neglect is having on the mental and physical well-being of affected individuals, including my own. The emotional and physical toll on our community is escalating, and the absence of clear pathways for support or redress is deeply distressing*." Email from Mark Lawler 3 June 2025 MLAW0000001. The option of making interim payments to people who have not yet had any compensation is one which David Foley thinks is not available to IBCA because no express power is granted to make interim payments in the Victims and Prisoners Act 2024 or the Infected Blood Compensation Regulations 2025; James Quinault in his evidence on 8 May 2025 said that though there would need to be a ministerial decision and Treasury approval, he thought that the Minister's view would be "*if it's possible for IBCA to make an interim payment to a group, then that would be clearly a very desirable thing to do since it means that some group, one group of people at least are not waiting right to the end of this process to get some of the compensation that they are due*." Third Written Statement of David Foley para 36 WITN7757011, James Quinault Transcript 8 May 2025 pp173-175 INQY1000284

At this stage, I should note that there is no dispute that claims need to be progressed fairly and as quickly as possible. It is thus important that prioritisation does not affect progress toward starting all claims for people within the living infected cohort, who are registered with a support scheme, before the end of 2025, as currently anticipated. While the prioritisation factors could be applied digitally to the data obtained from support schemes about people infected, this would inevitably incur some work and the rate of progress in contacting people means that IBCA's efforts are likely to be better focused elsewhere.[702]

In practice, therefore, I recommend that the prioritisation below is applied to people infected who are not registered with the support schemes and therefore have not had any support or compensation so that those within this cohort whose health is most seriously compromised or those who are elderly have their applications processed before others.

Applying the principle above would mean that, so far as can be done without prejudicing the overall speed of compensation, applications in respect of living infected persons who are not registered with the support schemes should be considered within their cohort as follows, in descending order of importance:

1. People who are within the last 12 months of life. Their word should be sufficient for this.
2. People who have advanced liver disease (are at Level 3 in the compensation scheme, or Stage 2 for the support schemes), with or without coinfection.
3. People who are elderly (the Inquiry suggests 75 and over).
4. Age (oldest first).

Applying the same principle in relation to applications in respect of the deceased infected would mean that applications related to the deceased infected should be considered within their cohort as follows, in descending order of importance:

1. Any beneficiary of the estate is within the last 12 months of life. Their word should be sufficient for this.
2. Any beneficiary of the estate is elderly (the Inquiry suggests 75 and over).
3. The deceased infected has not yet been recognised through any interim compensation.
4. Age of the oldest beneficiary of the estate (oldest first).

Applying the same principle in relation to people affected would mean that applications in respect of people affected should be considered within their cohort as follows, in descending order of importance:

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[702] As at 19 June 2025, 1,707 people infected and registered with a support scheme have been asked to start their claim and on average 100 more are being contacted each week. IBCA website Statistics: Compensation progress update: 19 June 2025

1. People who are within the last 12 months of life. Their word should be sufficient for this.
2. People who are elderly (the Inquiry suggests 75 and over).
3. The infection has not yet been recognised through any interim compensation with respect to the person infected, living or deceased, or a bereaved partner.
4. Children, both of whose parents were infected and died.
5. Age (oldest first).

If the Inquiry's recommendation in the chapter *People affected* is accepted and the Regulations are amended to the effect that a person is also an eligible affected person if they die between 21 May 2024 and 31 December 2029, they should continue to be considered as part of this cohort.

This would be a change to IBCA's current sequencing and mean that IBCA has three prioritised lists to work through in parallel alongside completing the people infected and registered with support schemes. This means that people who are within the last 12 months of life, whether infected, beneficiary of an estate of a deceased infected person or someone affected, whether registered with a scheme or not, will receive their compensation ahead of other people in their cohort. Similarly, the elderly in each cohort are prioritised to increase the likelihood that they live to see the recognition of their losses through compensation. Where someone has more than one claim related to the same infection (eg on behalf of the estate of someone deceased infected and as a person affected) they would be processed together.

People should be given the best available information as to where they stand in the lists, and this should be updated on a regular basis.

I recommend that: When IBCA opens up the service beyond people infected and registered with the support schemes, IBCA (i) update the sequencing to three cohorts, people infected and never compensated, the deceased infected, and people affected and (ii) adopt a scheme of prioritisation within each cohort which can be objectively applied and is easily understandable and (iii) progress the cohorts in parallel not sequentially.

Use of Lawyers and Third Parties to Assist IBCA

A rate-limiting factor in IBCA's early work was the number of claim managers they onboarded. As IBCA develops their service, I recommend that they view the provision of compensation as a system in which IBCA has the deciding role in accordance with Regulations, but need not itself perform every preparatory step towards that decision, such as obtaining evidence or documentation where others may be well placed to provide it.

IBCA has been seen by many of those who expressed concern to the Inquiry as having been reluctant to facilitate the involvement of their lawyers (where they have them). Appropriately, this seems to have been less apparent to them of late – but it is still important that IBCA recognises the independent legal firms they have contracted to provide legal support as part of the system for providing compensation.

One particular issue deserves comment. In the course of his evidence to the Inquiry on 8 May, David Foley said:

> "*we know a lot of people are represented, a lot of people aren't represented as well, and we have to make sure that our service is capable of providing for everybody. We do as -- you know, as Sir Robert recommended and the Government accepted, we do offer everybody, when they start a claim, the opportunity to have independent legal advice, and that is reiterated through the process of doing it as well. But because not everybody is represented, our service needs to be designed for everybody.*"[703]

Asked in respect of that answer:

> "*Wouldn't it be sensible for IBCA not just to say: well, yes, you can send what you want when we invite you, but to open up the scheme to say that anyone who, within the cohort, whichever cohort you are currently looking at, anyone who is in a position to do that, yes, send us your completed application form, send us your evidence pack. One of the examples I've been given was* [completed] *absolutely within days because everything was already there, and then it just needs checking by the claims manager, rather than the claims manager doing an enormous amount of legwork and their own calculations, and, of course, it has to be checked. Could you not do that whilst simultaneously obviously ensuring that you're not closing the service to those who don't want legal representation?*"

He responded:

> "*If we did it the way you were describing, we would undoubtedly be prioritising the claims of those who are represented and de-prioritising the claims of those who aren't represented. And that, I think, would pose a difficulty, in terms of being open to everybody. But everybody who does have that pack, when their claim starts, is entirely accepted and very welcome for them to present that.*"[704]

My comment on this is that if a system of priority of claims is introduced (as recommended above) it is that order of priority which should be followed. However, the system would undoubtedly speed up overall if more claims were prepared by legal representatives familiar with the details of the compensation scheme and presented by them to IBCA for review, or further discussion. In the course of his evidence, when asked if there was any reason why an application with a pre-prepared evidence pack, could not be accepted from a person's legal representatives, David Foley said "*So the first thing is, when a person begins their claim, they absolutely can send anything and everything that they would like to send to us.*

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[703] David Foley Transcript 8 May 2025 p59 INQY1000284

[704] David Foley Transcript 8 May 2025 p59-60 INQY1000284

So that is accepted and would be well received."[705] In the interests of speed, that message should be highlighted to applicants, and the use of legal support for this purpose should be positively encouraged.

One of the slower parts of the process is obtaining the necessary information to support a claim.

As recorded in the chapter on *Operation of the compensation scheme*, the UK Haemophilia Centre Doctors' Organisation submits that "*Haemophilia Centres are receiving requests for information from IBCA's Claims Managers as part of the compensation eligibility assessment. UKHCDO have significant concerns about the questions asked by IBCA, and the implications for the clinical teams and the therapeutic relationships they have with their patients.*"[706] This suggests time is being taken up both by IBCA, and by third parties it involves, in searches for documentation and data in ways that could be improved, and which may be in the hands of applicants or their legal representatives, and that in some cases their legal representatives could suggest better strategies for finding or that certain documentation is not in fact required.

The independent legal firms IBCA has contracted to provide legal support have considerable experience piecing together medical records related to the use and consequences of infected blood and blood products from different sources for the Inquiry and also litigation. Given the problems with record making and keeping described in the Inquiry Report,[707]

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[705] David Foley Transcript 8 May 2025 p59 INQY1000284

[706] The UKHCDO amplify these concerns saying "*Questions received from IBCA can be very time consuming to answer, in some cases up to four to six hours per claimant, sometimes even longer, as before confirming that the information is missing or not available, clinicians must go through the entire record page by page. The information must often be searched for in archived, often microfilmed records, making them very laborious to go through, with no guarantee of finding the information requested. In many instances, the data requested is not available or is unknowable, because records from the relevant time periods are often incomplete or missing, as noted during the course of the Inquiry itself. Clinicians are sometimes being given short deadlines (i.e. seven days) in which to respond to requests for information, which takes no account of their already considerable workloads and the length of time it may take to retrieve historical records from off-site storage. The random selection of Claimants "invited" by IBCA to make a claim is also unhelpful in terms of planning for the resource required for responding to requests for data. In general, the questions being asked appear to be based on modern diagnostic standards and technologies that were unavailable at the time of the infections in question. The questions suggest an incomplete understanding of the issues – they are often unanswerable because the information is not available, or the answers would be misleading (see below). There is no overlap, for example, between the period of risk for hepatitis C (prior to 1987 for concentrate and 1991 for plasma) and the availability of a test (from 1992). Consequently, the date of hepatitis C infection will be unknown for almost all patients. Asking questions which cannot be answered delays the process and increases clinicians' workloads for no benefit to patients. The Inquiry has already established that historic records are in many cases missing or incomplete – putting a new generation of clinicians in a position when they have to go through the process of establishing, again, that their patients' records are incomplete or missing is damaging to the patients' therapeutic relationships with those clinicians, undermines patient trust, and is detrimental to the delivery of patient care. The risk is that clinicians will be blamed if IBCA ask for data which is not available, or blamed for delays due to the time taken by clinicians to search for that information, and this will affect the relationship between patients and the new generation of clinicians who were not involved in the original infected blood tragedy.*" Written Submissions on behalf of UKHCDO paras 8-10 SUBS0000083. IBCA has not commented on these submissions, though invited to do so.

[707] See the chapter on Medical Records in the Inquiry Report where medical record keeping and the quality and content of medical records is discussed. Infected Blood Inquiry Report 20 May 2024 Volume 6 INQY0001006

IBCA is likely to benefit from consulting them as part of refining how it seeks information to avoid unnecessary delays, in addition to using their knowledge about the available records in individual cases – and to discover whether fruitless efforts have already been made to locate records which are missing or have been destroyed. All this will help save time. I encourage IBCA to do this.

Internal review

The system of decision and review (where the applicant wishes it) is a system which aims to ensure that the more obvious errors are corrected on review without the necessity of a tribunal hearing being needed.[708] If the matter still then proceeds as far as an appeal to the First-tier Tribunal, the Tribunal will hear from the individual and may hear from their legal representative (though the Tribunal system operates without public funding for legal representation). Accordingly, an applicant will be heard, but only at what is effectively the second stage of appeal. There will almost certainly be cases where what a person has to say orally may make a difference to the outcome. There should therefore be the possibility of accommodating this at the IBCA internal review stage. Because it is fundamental to the fair operation of the review process that written reasons for the original determination are provided, written reasons for the original decision should be provided.

I recommend that: IBCA consider making provision, either generally or in specific cases, for oral representations to be made where a decision is reviewed internally, and for the individual concerned and/or their lawyer to attend the appeal panel.

I also recommend that: Written reasons for the original decision must be provided so that the review process can operate fairly.

Commentary

The six recommendations in this chapter seek to increase speed of delivery overall and fairness and build on the progress IBCA has achieved of on average one hundred claims a week being started and IBCA being able to project that they will start the claims of all those who are infected and registered with a support scheme this calendar year.

IBCA's Board has had no prior sight of the recommendations, consistent with the Inquiry's approach of people being at the heart of the Inquiry and being the first to know any findings or recommendations made by the Inquiry. The recommendations are made in the light of the evidence and submissions received by the Inquiry, which are available on the Inquiry website, and with the goal of being constructive.

It will be for IBCA's Board, with their full knowledge of IBCA's operations, to consider the recommendations and either commit to implement them or give sufficient reason, in sufficient

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[708] There is a similar system where appeals against decisions by the DWP are concerned, known as "mandatory reconsideration". It has resulted in a significantly smaller number of appeals reaching the tribunal, and has speeded up the process for the individuals concerned.

detail for others to understand, why it is not considered appropriate to implement any one or more of them.

9.3 Transparency and involvement

The Second Interim Report recommended that "*the processes of the scheme need to be as transparent as legally possible*".[709]

There is no dispute about the principle of transparency – it is identified on IBCA's website as one of the "*7 simple principles*" that IBCA works to.[710]

It is closely linked to the involvement of people in the processes of IBCA – without it, people cannot be expected to contribute effectively to improvement of the processes, or to resolving difficulties that arise.

Sir Robert Francis in his August report recognised the link between transparency and involvement:

> "*IBCA will undertake to be transparent in its decision-making in setting up the processes by which applications will be received and assessed, and awards made, and will set up mechanisms for ensuring that this is informed by the involvement of the infected and affected communities in their production.*"[711]

David Foley reiterated in his written statement a commitment "*to the involvement of people infected and affected by the use of infected blood in IBCA's decision-making.*"[712] Sir Robert Francis emphasised his "*personal commitment and the organisation's commitment to involve the community in everything we do … what we are after is a two-way conversation about what we do.*"[713]

Thus transparency and involvement are to be treated as fundamental principles.

The provisions of the Public Bodies (Admission to Meetings) Act 1960 apply to some aspects of the governance of IBCA.[714] These require that meetings of the Authority are to be open to the public,[715] with (in general) at least three days' notice being given. The

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[709] Infected Blood Inquiry Second Interim Report 5 April 2023 p21 INQY0000453

[710] IBCA website About us RLIT0002959

[711] Recommendations of Sir Robert Francis KC to the Government on the proposals for a compensation scheme 12 July 2024 p15 RLIT0002466

[712] First Written Statement of David Foley para 11 WITN7757001

[713] Sir Robert Francis Transcript 8 May 2025 p76 INQY1000284

[714] Schedule 1(r) to the Public Bodies (Admission to Meetings) Act 1960 p9 RLIT0002971

[715] Subject to safeguards which are set out in the Act. These safeguards are important. Thus section 1(2) provides that a body may, by resolution, exclude the public from the whole or part of the proceedings whenever publicity would be prejudicial to the public interest by reason of the confidential nature of the business to be transacted, or for other special reasons stated in the resolution and arising from the nature of that business or of the proceedings and section 1(30 provides that the body may "*treat the need to receive or consider recommendations or advice from sources other than members, committees or sub-committees of the body as a special reason why publicity would be prejudicial to the public interest, without regard to the subject or purport of the recommendations or advice*". Sections 1(2) and 1(3) of the Public Bodies (Admission to Meetings) Act 1960 pp2-3 RLIT0002971

agendas for those meetings must be made available on request, along with copies of reports or other documents supplied to members in connection with the relevant agenda item.[716] It must necessarily follow that where IBCA's Board has approved written guidance or instructions to claim managers, or discussed papers produced on various issues relating to the interpretation or application of the Regulations, there is a strong legislative steer that these should be made available on request.

There is understandable concern in IBCA that transparency by revealing policies and guidance should not facilitate fraud. Sir Robert Francis spoke about this in the course of his evidence:

> "*When we started, we were advised by the relevant fraud experts that there were some 80 fraud risks attached to this scheme. And I know, from conversations I have had, the community are as worried about fraudulent people intervening as we are. However, we are absolutely aware that we mustn't use* [the] *sort of precautions against fraud as barriers that prevent genuine people applying. And as I've said already, our philosophy is very much we are supportive towards people in terms of the evidence they bring forward. But we do have to be realistic that, unfortunately, there are some people out there who would much like to intervene. So that is just one of many risks that we have to guard against … there are approaches, philosophies and policies about how you take risk, and it is David* [Foley]*'s job as accounting officer to remain within the requirements of that.*"[717]

The Inquiry understands that IBCA, informed by expert advice, is particularly concerned that AI can be used to generate large numbers of plausible, but fraudulent, applications, and that the publication of policies and processes, guidance to staff, and of forms may make this all the more possible.[718]

Whilst it is plainly proper for IBCA to take steps to protect against fraudulent claims, I do not accept the suggestion that this means that IBCA's policies and processes should not be published once they have been decided upon – and it is important that their formulation should be informed by the involvement of people infected and affected. IBCA has publicly committed to transparency, both through Sir Robert Francis' August report and as one of the main principles that it works to. It cannot live up to that commitment if it keeps secret the policies and processes which are relevant to its assessment of applications under the scheme.

Insofar as there are concerns about fraud arising from publication, it is noteworthy that the Department for Work and Pensions publishes numerous guidance and handbooks, including: the Work Capability Assessment handbook;[719] a Personal Independence

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[716] Section 1(4) of the Public Bodies (Admission to Meetings) Act 1960 p3 RLIT0002971

[717] Sir Robert Francis Transcript 8 May 2025 p48 INQY1000284

[718] From the response when this was put to David Foley under the Inquiry Rules 2006.

[719] A detailed guide for healthcare professionals who undertake Work Capability Assessments on behalf of the DWP. DWP explains that this is published to "*help people understand how we make decisions.*"

Payment assessment guide;[720] and multiple volumes of decision makers' guides, which provide guidance for DWP decision makers in relation to benefit entitlements, appeals, overpayments and suspension or termination of benefits.[721]

It is also noteworthy that the courts have criticised the existence of secret policies:

> "*The individual has a basic public law right to have his or her case considered under whatever policy the executive sees fit to adopt provided that the adopted policy is a lawful exercise of the discretion conferred by the statute: see In re Findlay [1985] AC 318, 338E. There is a correlative right to know what that currently existing policy is, so that the individual can make relevant representations in relation to it.*"[722]

Whilst the Supreme Court recognised that there may be "*compelling reasons not to publish some policies, for example, where national security issues are in play … What must, however, be published is that which a person who is affected by the operation of the policy needs to know in order to make informed and meaningful representations to the decision-maker before a decision is made.*"[723]

Lord Justice Sedley, giving the leading judgment in the Court of Appeal in *B v Secretary of State for Work and Pensions*, observed that if a policy has been formulated and is regularly used by officials:

> "*it is the antithesis of good government to keep it in the departmental drawer. Amongst its first recipients (indeed, among the prior consultees, I would have thought) should be bodies such as the Child Poverty Action Group and the Citizens Advice Bureaux. Their clients are fully as entitled as departmental officials to know the terms of the policy on the recovery of overpayments, so that they can either claim to be within it or put forward reasons for disapplying it, and so that the conformity of the policy and its application with principles of public law can be appraised.*"[724]

And as summarised by Mr Justice Fordham in the more recent case of *R (ZLL) v Secretary of State for Housing, Communities and Local Government* the duty of publication is "*linked, not only to the virtues of consistency and lack of arbitrariness, but also to the basic rights of*

DWP website *Work Capability Assessment handbook: for healthcare professionals* 6 September 2024 p2 RLIT0002976

[720] DWP website *Guidance for assessment providers carrying out assessments for Personal Independence Payment* 25 November 2024 RLIT0002977

[721] This guidance too is published "*to help people understand how we make decisions.*" DWP website *Decision makers' guide: staff guide* 28 October 2013 p2 RLIT0002978

[722] Lord Dyson in *R (Lumba) v Secretary of State for the Home Department* [2012] 1 AC 245 para 35 RLIT0002979

[723] Lord Dyson in *R (Lumba) v Secretary of State for the Home Department* [2012] 1 AC 245 para 38 RLIT0002979

[724] *B v Secretary of State for Work and Pensions* [2005] EWCA Civ 929 [2005] 1 WLR 3796 para 43 RLIT0002980

affected individuals: to make representations as to how their case should be decided, and to consider and make an informed challenge to an adverse decision."[725]

This case law supports what seems to me to follow naturally from giving transparency its proper value.[726] This is not in any sense to minimise the care that should be taken to avoid fraud. Whereas the balance is clear that in general IBCA should make public papers and proceedings at Board level, policies, guidance (including guidance in relation to specific regulations or specific issues which arise under the Regulations), and details of processes, it should not in my view publish its fraud prevention policies, unless there is compelling reason to do so. It is sufficient to record (as it has) that it has such policies, and takes care that they are applied; and I would expect the public to understand if a reason for their exclusion from a Board meeting or from seeing some of the papers at a Board meeting was that they specifically concerned fraud prevention policy and practices.

As I have already indicated, transparency should not only concern papers and proceedings at Board level, as covered by the 1960 Act. Most applicants deal with one claim manager, who may refer to a clinical assessor. There should be transparency about the advice of the clinical assessor; the factual basis on which that advice has been given;[727] and the reasons for that advice.[728] Such information must be shared with the individual in writing so that they, and where represented, their solicitor, can understand and where appropriate challenge the correctness of that advice. Similarly, where reference has been made to a particular policy or piece of advice in order to determine the entitlement of an applicant, it should be made available to them.

IBCA has thought it sufficiently important to the discharge of its functions for it to "*work with the Cabinet Office policy team*" to ensure that its staff "*understand in depth the policy intent behind each regulation*". IBCA's Lessons Learned document explains that this has enabled IBCA "*to be clear on what is within IBCA's power to define and what is not*" and in the latter

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[725] Mr Justice Fordham in *R (ZLL) v Secretary of State for Housing, Communities and Local Government* [2022] EWHC 85 (Admin) para 7(5) RLIT0002981

[726] The case law has been cited at some length in deference to the strength of concern there plainly is in IBCA about the need to protect the public money with which it deals from the risks of fraud.

[727] David Foley explains that clinical assessors are provided "*with any information they require in order to make their assessment which includes any relevant sections of the medical records.*" Fifth Written Statement of David Foley para 14 WITN7757022. Whilst not over-burdening the clinical assessor with an individual's medical records may have an advantage on the ground of efficiency, this suggests that it is down to the claim manager (who has no clinical expertise) to identify the "*relevant sections*" of the medical records to put before the clinical assessor. This reinforces the importance of ensuring that the individual and (where represented) their lawyer is told what information has been provided to the clinical assessor.

[728] David Foley explains that the individual will receive "*a written record at the declaration stage of the information that will be used to calculate the claim and the basis for the decisions.*" Fifth Written Statement of David Foley para 16 WITN7757022. It is equally important however that the individual receives a written communication of any advice from the clinical assessor. IBCA's clinical advisors' briefing pack states that after a session with a claim manager, the clinical advisor "*must complete the written section of the decision form with their advice and reasoning. This written advice should be clear and defensible, as it will be saved as part of the claim record and could be scrutinised in any appeal or audit.*" Clinical Advisors' Briefing Pack - IBCA Programme 2025 p6 WITN7757023. It should therefore be straightforward for the clinical assessor's advice and reasoning to be shared with the individual whose eligibility and compensation are being assessed.

case, to "*get more detail on intent so we are able to explain this where possible whilst still being clear that is regulations and not IBCA policy.*"[729]

The Inquiry understands that IBCA does not consider it part of its role to publish the products of the work described above. However, IBCA's understanding of the policy intent behind each regulation is plainly material to (or at the very least has the potential to inform) the exercise of IBCA's functions – why else would it have undertaken this exercise? And given that one purpose at least of doing so was to be "*able to explain this where possible*" it is unclear why there is resistance to sharing IBCA's understanding with people infected and affected and their legal representatives. There are three advantages, at least, to doing so. One, if there have been behind-the-scenes discussions between IBCA and the Cabinet Office with regard to the purpose of each of the regulations, it is in the interests of transparency (and avoids the perception of unfairness and one-sidedness) for that to be made public. Withholding such material only fuels suspicion that there is something to hide – publication dispels such concerns. Second, there may be a practical advantage to doing so – if applicants and their lawyers understand how and why IBCA is approaching a particular regulation in a particular way, that may make the submission of the individual's application and the provision of relevant evidence by that individual more focused and efficient. Third, it may be of course that the Cabinet Office policy team and/or IBCA are wrong about a particular regulation – but only if their understanding is shared can an applicant or their legal representative be in a position to challenge it.

Though this chapter has addressed transparency as a matter of fundamental principle, its practical benefits should not be underestimated. Knowing the approach of IBCA, and the documents it regards as necessary, assists applicants and their legal representatives in collecting material and preparing an application at an early stage. This helps speed up the process by making it more likely that relevant material will be made available more quickly for IBCA to review.

If transparency and involvement are treated as essential guiding principles (as they should be) they must be honoured by observing them, and not treated as considerations which are secondary to risks of fraud.

I recommend that: IBCA should publish:

- **guidance, advice or instructions to claim managers including guidance on specific regulations or issues which arise under the Regulations**[730]
- **work undertaken by IBCA with the Cabinet Office's policy team to ensure that IBCA understands "*in depth the policy intent behind each regulation*"**[731]

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[729] IBCA Lessons Learned from early compensation claims 2 May 2025 para 1b WITN7757020

[730] See for example IBCA Claim Managers' Playbook May 2025 IBCA0000001, IBCA Key determinations May 2025 IBCA0000002

[731] IBCA Lessons Learned from early compensation claims 2 May 2025 p1 WITN7757020

- **the papers that have been produced by IBCA addressing specific issues within the Regulations – such as the "dating principles paper", the "paper on HIV infection dating" and the "Hepatitis B (post-1972) paper"[732] – and any future similar papers**
- **IBCA's approach to the Hepatitis severity bandings in Schedule 1 to the 2025 Regulations**
- **minutes of the meetings of IBCA's Board (except where publicity would be prejudicial to the public interest by reason of the confidential nature of the business to be transacted, or for other special reasons stated by resolution of the Board and arising from the nature of that business or of the proceedings)[733]**

I also recommend that: In respect of any case in which the advice of a clinical assessor has been given, in relation to the person concerned (and no more widely except with the consent of that person) that person should be told the factual basis on which that advice has been given;[734] and the reasons for that advice.[735] Such information must be shared with the individual in writing in sufficient detail so that they, and where represented, their solicitor, can understand and where appropriate challenge the correctness of that advice.

This recommendation does not extend to fraud prevention policies, processes and practices, but it should be recognised that though protective measures are clearly needed to guard against the risk of fraud, there is no good reason why a lack of transparency as to internal guidance, policies and other important material should be one of them.

Turning to involvement and inclusion, it was the recommendation of the Inquiry in its Second Interim Report that there should be an advisory board of the compensation body, which

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[732] See for example, IBCA Draft paper for discussion *Date Treatment* March 2025 IBCA0000005, IBCA Draft paper for discussion *HIV eligibility* April 2025 IBCA0000005, IBCA Draft paper for discussion *Determining Hep B eligibility* April 2025 IBCA0000007, IBCA Draft ExCo paper *Hep B eligibility determinations after 1972* April 2025 IBCA0000008

[733] This replicates an important safeguard contained in s1(2) and (3) of the Public Bodies (Admission to Meetings) Act 1960 pp2-3 RLIT0002971

[734] David Foley explains that clinical assessors are provided "*with any information they require in order to make their assessment which includes any relevant sections of the medical records.*" Fifth Written Statement of David Foley para 14 WITN7757022. Whilst not over-burdening the clinical assessor with an individual's medical records may have an advantage on the ground of efficiency, this suggests that it is down to the claim manager (who has no clinical expertise) to identify the "*relevant sections*" of the medical records to put before the clinical assessor. This reinforces the importance of ensuring that the individual and (where represented) their lawyer is told what information has been provided to the clinical assessor.

[735] David Foley explains that the individual will receive "*a written record at the declaration stage of the information that will be used to calculate the claim and the basis for the decisions.*" Fifth Written Statement of David Foley para 16 WITN7757022. It is equally important however that the individual receives a written communication of any advice from the clinical assessor. IBCA's clinical advisors' briefing pack states that after a session with a claim manager, the clinical advisor "*must complete the written section of the decision form with their advice and reasoning. This written advice should be clear and defensible, as it will be saved as part of the claim record and could be scrutinised in any appeal or audit.*" Clinical Advisors' Briefing Pack - IBCA Programme 2025 p6 WITN7757023. It should therefore be straightforward for the clinical assessor's advice and reasoning to be shared with the individual whose eligibility and compensation are being assessed.

should include beneficiaries ("*it is important that decisions about those who should receive compensation are not made without them*").[736] Further, it was a recommendation of the Inquiry that "*those set to benefit from the scheme (people infected and affected) must have a central influence on its decision-making and operation*". It is therefore to be welcomed that, as the chapter on the *Operation of the Compensation Scheme* records, IBCA's Board has been "*finalising its arrangements about how it would like* [an advisory board comprising people infected and affected] *to be built.*"[737] The importance of establishing such a board and ensuring the involvement of people infected and affected cannot be overstated.

I recommend that: A formal role be given within IBCA for an advisory body consisting of people infected and affected, covering a range of experience broadly representative of those groups, and (if those groups so wish) including clinicians covering the major relevant disciplines of hepatitis and liver disease, HIV, transfusion, haemophilia, psychosocial aspects and palliative care. The advisory body should choose its chair, and the chair should be formally invited to each and every meeting of the Board of IBCA, and be given observer status.

The chapter on the *Operation of the Compensation Scheme* and the presentation ahead of the Inquiry hearings documented concerns about uninformative responses from IBCA to suggestions made by people infected and affected and frustrations that people were not being listened to.

I recommend that: To build confidence that IBCA is actively listening to people infected and affected, IBCA adopt more of a structured response to contributions from people infected and affected. Consideration should be given, as a minimum, to making a contemporaneous record of IBCA's understanding of the matters that had been raised in meetings with people infected and affected and setting out IBCA's response to each point.

This Additional Report necessarily only addresses issues that have arisen during the making of the Regulations and award of compensation to fewer than 500 people infected and registered with the support schemes. More issues will emerge and individuals – like the mother quoted at the end of the chapter on *HIV transmitted before 1982* – should not feel that they are alone when this happens.

I recommend that: The Government and IBCA establish a mechanism by which individuals or organisations may raise concerns which arise about any aspect of the scheme which from time to time is troubling them. The mechanism is intended to help continuous improvement of, and/or aid understanding of, any aspect of the scheme. It should involve identifying a person or body to whom any such concern should be expressed, whose role it is to consider the concern, log it, and ensure that a person of appropriate seniority either responds to it in writing, or ensure that it is

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[736] Infected Blood Inquiry Second Interim Report 5 April 2023 p19 INQY0000453

[737] David Foley Transcript 8 May 2025 p17 INQY1000284

placed on the agenda for the next meeting of the advisory body or IBCA's Board or is onsidered by the Cabinet Office and Minister as appropriate.

Support for people infected and affected

The Full Government Response to the Infected Blood Inquiry's May 2024 Report was published on 14 May 2025. Two of the recommendations are relevant to recognition of what happened to people, and therefore to compensation, and have been accepted in full or in principle. Support is particularly needed as individuals navigate the complexities of the compensation scheme, and their anxieties about it.

> **2. Recognising and remembering what happened to people**
>
> (a) A permanent memorial be established in the UK and consideration be given to memorials in each of Northern Ireland, Wales and Scotland. The nature of the memorial(s), their design and location should be determined by a memorial committee consisting of people infected and affected and representatives of the governments. It should be funded by the UK government.
>
> (b) A memorial be established at public expense, dedicated specifically to the children infected at Treloar's school. The memorial should be such as is agreed with those who were pupils at Treloar's.
>
> (c) There should be at least three events, approximately six months apart, drawing together those infected and affected, the nature and timing of which should be determined by a working party as described above, facilitated by some central funding.
>
> **10. Giving patients a voice**
>
> (a) That the patient voice be enabled and empowered by the following measures:
>
> …
>
> (ii) that the following charities receive funding specifically for patient advocacy: the UK Haemophilia Society, the Hepatitis C Trust; Haemophilia Scotland; the Scottish Infected Blood Forum; Haemophilia Wales; Haemophilia Northern Ireland; and the UK Thalassaemia Society.
>
> (iii) that favourable consideration be given to other charities and organisations supporting people infected and affected that were granted core participant status (as listed on the Inquiry website) to continue to provide support for at least the next 18 months. Further support should be reviewed at that stage with a view to it continuing as appropriate. ...[738]

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[738] Infected Blood Inquiry Report 20 May 2024 Volume 1 p223, p275 INQY0001001, Government Response to the Infected Blood Inquiry 14 May 2024 pp26-27, pp71-73 RLIT0002982

The Inquiry's recommendations 10(a) (ii) and (iii) have been accepted by the Government. The evidence given to the Inquiry by Kate Burt (for the Haemophilia Society), Samantha May (for the Hepatitis C Trust), Lynne Kelly (Haemophilia Wales), Bill Wright (Haemophilia Scotland) and Nigel Hamilton (Haemophilia Northern Ireland) on 7 May showed some of the work those organisations have been doing to give a voice to people in the infected blood community. Their evidence left no one in doubt about the huge strains that charities and organisations supporting people infected and affected have been under since the compensation scheme was announced on the day after the Inquiry Report was published. No one could doubt that they are struggling to cope with the volume and nature of the concerns and feeling of powerlessness. They have been trying to help people whose distress and worry is being accentuated not only by delay, but by a sense that they have had no meaningful involvement in the scheme, who now looked to these charities and organisations to do what they could to help.

I am aware that offers of financial support have been under discussion with three of the charities.[739] I have no comment to make on that, save to say that it is now more necessary than ever. It is important that this recommendation, now made over a year ago, is fulfilled as soon as is reasonably possible.

The mutual support and solidarity of being able to come together, to which recommendation 2(c) of the 2024 Inquiry Report relates, is much needed after the past year and the need for predictable financial support to the charities and organisations the Government and IBCA has relied upon to support people is obvious.

Finally, from 10 June services to provide bespoke psychological support for people infected and affected have been in place across the whole of the UK.[740] It is important to ensure that these services are adequately resourced in each of the four nations in the years ahead.

9.4 Adjusting the provisions of the scheme

The account of the way the scheme was designed, contained in Chapter 2 on *Design of the compensation scheme*, reveals there was no meaningful involvement of people infected and affected at a formative stage, and that there was limited time for discussion about details of the scheme between the day that the Victims and Prisoners Act 2024 was enacted by Parliament and the deadline for Regulations to be made. It was therefore not surprising that some anomalies have been revealed, that some provisions have had

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[739] Nick Thomas-Symonds Transcript 7 May 2025 pp172-175 INQY1000283, Letter from the Haemophilia Society, Hepatitis C Trust and UK Thalassaemia Society to the Parliamentary Under-Secretary of State for Public Health and Prevention 5 June 2025 HSOC0029919. This letter states their view that: "*The Department of Health and Social Care has produced an inadequate response to the Infected Blood Inquiry's Recommendation 10 which seeks to safeguard patient advocacy for the communities at the heart of the scandal through statutory funding ... The DHSC offer fails to honour the complex and critical need for on-going patient advocacy …*"

[740] Specialist psychological services have been available in Scotland, Northern Ireland and Wales for some years. The Infected Blood Psychological Service in England accepted self-referrals from 10 June 2025. See the Written Statement of Dr Sarah Helps WITN7769001

unintended adverse effects or worked injustice, and that some provisions that might have been expected are absent.

Chapters 4 to 8 set out the detailed reasoning for each recommendation, so only the briefest of introductions is needed here.

Chapter 4 examines the exclusion of people infected with HIV through blood and blood products before 1 January 1982 from eligibility under the compensation scheme, which I find to be both illogical and unjust.

I recommend that: An amendment to the Regulations be made as soon as possible to remove the reference to 1 January 1982 from Regulation 3.

Chapter 5 on Hepatitis examines in detail the concerns about the Special Category Mechanism and equivalents, consequences of treatment with interferon, extra-hepatic manifestations of Hepatitis and serious fibrosis.

I recommend that: People infected with Hepatitis B or C who have received a course of treatment with or based on interferon should be recognised as entitled to core awards at Level 3.

I also recommend that: The Government reconsider whether to maintain its rejection in February 2025 of the recommendations of Sir Robert Francis KC and advice from the Infected Blood Inquiry Response Expert Group of August 2024, which was expressly accepted at the time by the Government, to introduce (as one of six health impact groups which would justify a severe health condition award) the following for people infected with Hepatitis B and Hepatitis C:

> ***"Other Hepatitis C associated extra hepatic disorders resulting in long-term severe disability. This includes those currently assessed as the following category on IBSS:***
>
> ***- Hepatitis Special Category Mechanism (EIBSS)***
>
> ***- 'Severely Affected' Hepatitis C (SIBSS)***
>
> ***- Hepatitis C Stage 1 Plus (WIBSS)***
>
> ***- Hepatitis C Stage 1 Enhanced Payments (NIIBSS)"***

Chapter 6 deals from 6.2 to 6.7 with some of the unfortunate and unfair consequences of the current wording of the Regulations, which are capable of remedy by simple measures unlikely to cause any significant delay in the delivery of compensation scheme payments.

In Chapter 6.2 in respect of the conditions for a Severe Health Condition award in respect of severe psychological harm:

I recommend that: The approach of the Infected Blood Psychology Service is adopted so that both a diagnosis made by a psychiatric professional and a formulation-based opinion of all qualified psychological and counselling professionals are accepted

as sufficient evidence of severe psychological harm and that such evidence should qualify a person for a supplementary Severe Health Condition award without the additional need to demonstrate a period of consultant-led secondary mental health treatment or assessment/treatment as an inpatient.

In Chapter 6.3 in respect of the effects of the generalised assumptions in Regulation 20(6)(c) that after a date known as "*the year of effective treatment*" a person infected with Hepatitis will be able to return to work and, if able to work, will be able to find it:

I recommend that: For the calculation of Financial Loss awards for Hepatitis B, people born after 1953 should be treated like those born in or before 1953 on provision of evidence that their health did not improve or that it remained difficult to find work from 2009. For the calculation of Financial Loss awards for Hepatitis C, people born after 1961 should be treated like those born in or before 1961 on provision of evidence that their health did not improve or that it remained difficult to find work from 2017.

Chapter 6.4 concerns Regulation 20(7) which contains provisions to deem the level of severity of infection with Hepatitis for which someone infected should be compensated, where it is known by the time of application to the scheme that that person has an infection of Level 3 or above, but there is insufficient evidence to show for any earlier year what the severity level was for that year. These provisions can fail in their purpose if there is sufficient evidence in respect of an earlier year that, during it, the person concerned reached Level 3 or more, but there is insufficient evidence as to the severity level of their infection before that. This is because the provisions use only one date from which to deem what the progression must have been up to that date – and this sole date is the date of application to the scheme. A simple change works justice:

I recommend that: Where the level of severity of a person's infection at Level 3 or more has been established to IBCA's satisfaction in relation to a given year, but it is not known when it reached Level 3 or more, the legislative provisions should apply to deem the level of severity in the years which preceded that given year.

Chapter 6.5 is about Regulation 14(2) of the 2025 Regulations, which requires that an application for an infected core payment must be accompanied by evidence which (amongst other matters) establishes "*the date on which the diagnosis* [of HIV, Hepatitis C or Hepatitis B] *was given*". The date of diagnosis **with HIV** is relevant to the calculation of the financial loss (core) award for a person with HIV: this is because regulation 20(4) and (5) calculates the annual amounts for payment by reference to "*the year in which P was diagnosed as infected with HIV*". The date of diagnosis with **Hepatitis C** or **Hepatitis B** does not, however, affect the calculation of the core award. Though in order to calculate the appropriate awards for increasing severity of hepatitis infections there needs to be an effort to find out when a person's infection reached a severity Level 3 or above (it will otherwise be assumed under the deeming provisions in Rule 20(7)), evidence of the actual date of diagnosis with Hepatitis is not used in calculating the core award. Since evidence of a precise date of diagnosis is so notoriously difficult to find in very many cases of Hepatitis, and since it is unlikely to serve any useful purpose when established, it is a provision which is better removed so far as it relates to cases of Hepatitis.

I recommend that: Regulation 14(2)(c) be amended to remove the requirement for evidence of the date of diagnosis of Hepatitis B or C. An appropriate redraft to achieve this would be: "*where the diagnosis mentioned in sub-paragraph (a) is one of HIV, the date on which it was given*."

Chapter 6.6 is about Regulation 7, which determines how income losses and care costs can be separated into past and future portions. A person who opts to continue to receive support scheme payments receives an amount in respect of income loss which is 75% of that which a person in identical circumstances, save that they choose not to receive support scheme payments in future, will receive. This is because the formula used to separate past from future losses applies a figure ("x") which has that effect. So far as care costs are concerned, a justification for the past value of care being reduced to 75% is that whereas future care can be valued by its cost when commercially provided, it is highly likely that past care was provided gratuitously, and thus "cost" around 25% less. However, the cost per hour is only one part of the total cost of care. The other parts are the number of hours, and the quality of the care needed – accommodating unsocial hours, responding to urgent needs, coping with the need for privacy in respect in particular of HIV but also Hepatitis C and Hepatitis B. The evidence to the Inquiry is to the effect that needs for care were particularly high at times in the past such that when the hours of care are considered there is no justification for the view that the value of past care should be discounted.

I recommend that: "x" be removed from the equation set out in Regulation 7.

The same chapter addresses concern about the narrowness of the provisions for establishing exceptional reduced earnings:

I recommend that: The Cabinet Office consult on whether the evidential requirements for exceptional reduced earnings are likely to prove a barrier to people who have sufficient evidence that their eligibility for such an award could with confidence be established on a balance of probabilities, and if so to consider what if any provision might be introduced to enable them to access an award.

In Chapter 6.7 in respect of concerns that the scope of the unethical research practices award is too narrow and that the amount of the award is too small.

I recommend that: (1) Where there is evidence that an individual was the victim of unethical research practices IBCA should be authorised to make an unethical research practices award to that individual and (2) When considering the evidence IBCA applies the wider definition of research explained in the chapter on *Unethical Research*.

I also recommend that: The Minister consider whether the £10,000 (£15,000 for Treloar's pupils) should in justice be increased and further decides what sum he considers accords most closely with the general public's sense of justice and fairness in respect of an individual being subject of research without informed consent.

The question of whether there should be a supplementary route for people affected is addressed in Chapter 7:

I recommend that: The Minister give consideration to there being a supplementary route for the affected. This could include opening the supplementary award for severe psychological harm to people affected. He should involve parents, children, siblings, partners and carers, and their legal representatives if wished, in this consideration.

Chapter 7 also addresses the consequences of the length of time it has taken and will take for compensation to be rolled out, which, coupled with the policy of IBCA to resolve the claims of people affected after those infected, means that it will take longer than was reasonably anticipated when the Inquiry recommended in its Second Interim Report that the claim of a person affected should die with them, and not form part of their estate. The effects of delay deserve to be remedied.

I recommend that: The Regulations be amended such that where someone who would be an eligible affected person dies between 21 May 2024 and 31 December 2029, their claim does not die with them but becomes part of their estate.

Chapter 8 discusses the fact that a bereaved partner was entitled to continue to receive 75% of the annual support payments that were being received by their infected partner.[741] Those whose partners died on or before 31 March 2025 will continue to be eligible for and to receive these payments: however, under the compensation scheme any person whose partner dies on or after 1 April 2025 will not be so entitled: the payments from the support schemes stop on their partner's death.

I recommend that: The IBSS cut-off date of 31 March 2025 be reviewed, that the scheme should as soon as possible reinstate support payments to partners bereaved after 31 March 2025 until such time as they receive compensation and that they should have a continuation of those payments as an option in their compensation package.

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[741] Under the schemes, upon the death of a registered beneficiary, the surviving partner could receive the equivalent regular payment for one year at 100% and for subsequent years payments at a rate of 75% of the beneficiary payment.

9.5 Recommendations

The complete list of recommendations in this Additional Report is as follows:

1. Speed and fairness

(a) The scheme be opened to registration to everyone who may be eligible.

(b) There be forms (devised by IBCA) for people to register and apply for a core award and the supplementary awards with/without the necessary evidence and with/without calculation of compensation, and as an intermediate step that IBCA provide the option to move straight to the declaration stage for individuals providing all the necessary information.

(c) IBCA include a prominent reference to the availability of legal support paid by IBCA on all registration and application forms and in public information about the compensation scheme and that the Solicitors Regulation Authority remind solicitors of their obligations.

(d) When IBCA opens up the service beyond people infected and registered with the support schemes, IBCA: (i) update the sequencing to three cohorts, people infected and never compensated, the deceased infected, and people affected and (ii) adopt a scheme of prioritisation within each cohort which can be objectively applied and is easily understandable and (iii) progress the cohorts in parallel not sequentially.

(e) IBCA consider making provision, either generally or in specific cases, for oral representations to be made where a decision is reviewed internally, and for the individual concerned and/or their lawyer to attend the review panel.

(f) Written reasons for the original decision must be provided so that the review process can operate fairly.

2. Transparency and involvement

(a) IBCA should publish:

- guidance, advice or instructions to claim managers
- work undertaken by IBCA with the Cabinet Office's policy team to ensure that IBCA understands "*in depth the policy intent behind each regulation*"
- the papers that have been produced by IBCA addressing specific issues within the Regulations – such as the "dating principles paper", the "paper on HIV infection dating" and the "Hepatitis B (post-1972) paper" - and any future similar papers
- IBCA's approach to the Hepatitis severity bandings in Schedule 1 to the 2025 Regulations

- minutes of the meetings of IBCA's Board (except where publicity would be prejudicial to the public interest by reason of the confidential nature of the business to be transacted, or for other special reasons stated by resolution of the Board and arising from the nature of that business or of the proceedings)

(b) In respect of any case in which the advice of a clinical assessor has been given, in relation to the person concerned (and no more widely except with the consent of that person): that person should be told the factual basis on which that advice has been given; and the reasons for that advice. Such information must be shared with the individual in writing in sufficient detail so that they, and where represented, their solicitor, can understand and where appropriate challenge the correctness of that advice.

(c) A formal role be given within IBCA for an advisory body consisting of people infected and affected, covering a range of experience broadly representative of those groups, and (if those groups so wish) including clinicians covering the major relevant disciplines of hepatitis and liver disease, HIV, transfusion, haemophilia, psychosocial aspects and palliative care. The advisory body should choose its chair, and the chair should be formally invited to each and every meeting of the Board of IBCA, and be given observer status.

(d) To build confidence that IBCA is actively listening to people infected and affected, IBCA adopt more of a structured response to contributions from people infected and affected. Consideration should be given, as a minimum, to making a contemporaneous record of IBCA's understanding of the matters that had been raised in meetings with people infected and affected and setting out IBCA's response to each point.

(e) The Government and IBCA establish a mechanism by which individuals or organisations may raise concerns which arise about any aspect of the scheme which from time to time is troubling them. The mechanism is intended to help continuous improvement of, and/or aid understanding of, any aspect of the scheme. It should involve identifying a person or body to whom any such concern should be expressed, whose role it is to consider the concern, log it, and ensure that a person of appropriate seniority either responds to it in writing, or ensure that it is placed on the agenda for the next meeting of the advisory body or IBCA's Board or is considered by the Cabinet Office and Minister as appropriate.

3. HIV transmitted before 1982

(a) An amendment to the Regulations be made as soon as possible to remove the reference to 1 January 1982 from Regulation 3.

4. Hepatitis

(a) People infected with Hepatitis B or C who have received a course of treatment with or based on interferon should be recognised as entitled to core awards at Level 3.

(b) The Government reconsider whether to maintain its rejection in February 2025 of the recommendations of Sir Robert Francis KC and advice from the Infected Blood Inquiry Response Expert Group of August 2024, which was expressly accepted at the time by the Government, to introduce (as one of six health impact groups which would justify a severe health condition award) the following for people infected with Hepatitis B and Hepatitis C:

> "*Other Hepatitis C associated extra hepatic disorders resulting in long-term severe disability. This includes those currently assessed as the following category on IBSS:*
>
> *- Hepatitis Special Category Mechanism (EIBSS)*
>
> *- 'Severely Affected' Hepatitis C (SIBSS)*
>
> *- Hepatitis C Stage 1 Plus (WIBSS)*
>
> *- Hepatitis C Stage 1 Enhanced Payments (NIIBSS)*"

(c) For the calculation of Financial Loss awards for Hepatitis B, people born after 1953 should be treated like those born in or before 1953 on provision of evidence that their health did not improve or that it remained difficult to find work from 2009. For the calculation of Financial Loss awards for Hepatitis C, people born after 1961 should be treated like those born in or before 1961 on provision of evidence that their health did not improve or that it remained difficult to find work from 2017.

(d) Where the level of severity of a person's infection at Level 3 or more has been established to IBCA's satisfaction in relation to a given year, but it is not known when it reached Level 3 or more, the legislative provisions should apply to deem the level of severity in the years which preceded that given year.

(e) Regulation 14(2)(c) be amended to remove the requirement for evidence of the date of diagnosis of Hepatitis B or C. An appropriate redraft to achieve this would be: "*where the diagnosis mentioned in sub-paragraph (a) is one of HIV, the date on which it was given*."

5. Severe psychological harm

(a) The approach of the Infected Blood Psychology Service is adopted so that both a diagnosis made by a psychiatric professional and a formulation-based opinion of all qualified psychological and counselling professionals are accepted as sufficient evidence of severe psychological harm and that such evidence should qualify a person for a supplementary Severe Health Condition award without the additional need to demonstrate a period of consultant-led secondary mental health treatment or assessment/treatment as an inpatient.

6. Financial and care losses

(a) "x" be removed from the equation set out in Regulation 7.

(b) The Cabinet Office consult on whether the evidential requirements for exceptional reduced earnings are likely to prove a barrier to people who have sufficient evidence that their eligibility for such an award could with confidence be established on a balance of probabilities, and if so to consider what if any provision might be introduced to enable them to access an award.

7. Unethical research

(a) Where there is evidence that an individual was the victim of unethical research practices IBCA should be authorised to make an unethical research practices award to that individual.

(b) When considering the evidence IBCA applies the wider definition of research explained in the Infected Blood Inquiry Additional Report chapter on *Unethical Research*.

(c) The Minister consider whether the £10,000 (£15,000 for Treloar's pupils) should in justice be increased and further decides what sum he considers accords most closely with the general public's sense of justice and fairness in respect of an individual being subject of research without informed consent.

8. People affected

(a) The Minister give consideration to there being a supplementary route for people affected. This could include opening the supplemental award for severe psychological harm to people affected. He should involve parents, children, siblings, partners and carers, and their legal representatives if wished, in this consideration.

(b) The Regulations be amended such that where someone who would be an eligible affected person dies between 21 May 2024 and 31 December 2029, their claim does not die with them but becomes part of their estate.

9. Bereavement after 31 March 2025

(a) The IBSS cut-off date of 31 March 2025 be reviewed, that the scheme should as soon as possible reinstate support payments to partners bereaved after 31 March 2025 until such time as they receive compensation and that they should have a continuation of those payments as an option in their compensation package.

10 Concluding Remarks

In the Inquiry Report of May 2024, I anticipated that within a year I should be able to tell the Minister that the Inquiry had fulfilled its terms of reference. I added that "*I shall do so only if I am satisfied that there is no further role I can usefully play in preventing delay*." Though I recognised the possibility of delay, I did not foresee quite what has occurred. I did not expect that the Inquiry would have to issue a further report, because I hoped – indeed, expected – there would be no need for one. However, such were the numbers of people who wrote to the Inquiry to express serious concerns, such was the range and variety of the people who wrote,[742] and such was the force of the concerns they expressed, that it would have been unconscionable for the Inquiry not to have responded. More issues emerged than delay. They were serious. Together they led to the necessity of the Inquiry holding further short hearings.

In the Inquiry Report in 2024, I wrote that one of the lessons to be learned from what had happened was:

> **People affected by decisions need to be involved in them.**
>
> – This is true not only in respect of their own medical treatment. It is necessary for any support schemes to involve the people affected by them. (See the chapters on the *Macfarlane Trust, Eileen Trust, Caxton Foundation, Skipton Fund* and *National Support Schemes*).
>
> – There is a fear, now, that the design of the compensation scheme to meet the recommendations made in the second report of the Inquiry may not involve those people whom it most centrally affects.[743]

The following day the Government announced a detailed scheme of compensation which had been drafted without **any** direct involvement of the people it most centrally affected.

This has led to many of the problems dealt with in this Additional Report. If the principle that "*People affected by decisions need to be involved in them*" had been followed, it is likely that most or all of these could have been avoided.

A central casualty of the events described in the 2024 Inquiry Report was trust in authority. The words of Government, of Parliament, echoed then or shortly afterwards by the national governments, all offered the prospect on 20 May 2024 that trust might be restored.

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[742] Including a number writing to the Inquiry for the first time.

[743] This is from the chapter on *Lessons to be Learned*. Infected Blood Inquiry Report 20 May 2024 Volume 1 p218 INQY0001001

Anyone who listened to the evidence of organisations and individuals presented on 7 May 2025, and who read the statements and the letters published by the Inquiry, will have been in no doubt that trust has not yet been regained but has instead been further damaged and that people have been harmed yet further by the way in which they have been treated. But there may yet be a prospect that some trust can be restored, though it will require more than goodwill, more than warm words, and more than statements of intent to secure it. It will require actions that demonstrate that the people centrally affected by decisions have truly been listened to and that they will continue to be listened to. It will require that they be given the opportunity to contribute to the decision-making of the Government and of IBCA from now onwards.

The number of people who said how glad they were that the Inquiry responded as it did paid testament to the need to express their widespread, increasingly desperate, concerns – about the compensation scheme, its speed, its fairness, and the fact many felt they had spoken, and been heard but had not been listened to – and to look to action being taken. Despite the emotional toll of the past months, people came to the Inquiry's hearings in numbers, hopeful that change was possible. They heard Nick Thomas-Symonds place significant emphasis on speed of delivery and state that he is open to considering changes in the scheme where they are merited, provided that no significant time is lost. David Foley for his part stressed a number of times that input was welcome into the operations of IBCA, and Sir Robert Francis has been consistent throughout his involvement with the Inquiry in promoting the importance of meaningful involvement of people, infected and affected, in something so important to them. Nick Thomas-Symonds, David Foley, and Sir Robert Francis, from their own perspectives, have noted powerful contributions from the members of the panel of campaigners and organisational representatives. They will have heard that improvements are urgently needed to the speed, transparency, involvement and detailed fairness with which the scheme operates. The actions they take next will show if they have not only heard, but listened.

Time, more experience delivering compensation to people, and ongoing meaningful involvement, will almost undoubtedly reveal further improvements which can and should be made to the scheme, or that aspects of it are being misunderstood or misapplied. There needs to be a process by which concerns can be raised and changes or improvements made in response where appropriate. I have recommended that the Government and IBCA establish a specific mechanism for this: Recommendation 2(e).

This was also the subject of Recommendation 12 in the 2024 Inquiry Report, speaking generally of all inquiries, when I recommended that a Parliamentary Committee should review progress towards responding to an inquiry's recommendations, and, to the extent that those recommendations are accepted, review progress towards implementation. This recommendation, in common with all the recommendations made by the Inquiry, has been accepted by the Government (in the case of this recommendation, in principle, since the setting up and functions of a Parliamentary Committee are a matter for Parliament). It has not yet been put into effect. The need for follow up and scrutiny of recommendations remains unanswered in practice: it is undesirable that the ability of an inquiry itself to follow up recommendations has to depend on the scope of its Terms of Reference, as in the case of this Inquiry.[744] I urge that time is found in the Parliamentary calendar to give effect to an appropriate mechanism for follow up.

If Recommendation 2(e) in this Additional Report is given effect to (and if in addition Parliament creates the mechanism recommended in Inquiry Recommendation 12 from the May 2024 Inquiry Report) there will be a clear route by which people's concerns can be raised and properly addressed in the future. Once there is a suitable mechanism for these concerns to be raised, listened to and acted upon the Inquiry's role will be complete.

This Additional Report has focused on matters that could be improved in the way the scheme has been working, and in remedying some of the problems caused by provisions included in the legislative scheme itself, or by omissions from them. Working their way through these, a reader might be inclined to think that the scheme as a whole is failing.

Yet it is fair to record that the Government has taken major steps: it has introduced a compensation scheme, set up and financed an arm's length body whose sole focus is delivering that compensation, and reserved a very considerable allocation of funds for the purpose. The Minister has helped IBCA to be in a position to say that by the end of this year they expect to have begun claims for all living infected people registered with support schemes. This is true. But it should not obscure the fact that there is more to getting a compensation scheme right than making legislation and allocating finance, vital though that is. Whereas it would be unfair to suggest that the scheme viewed overall is failing, aspects of it certainly are, as this Additional Report shows. The Additional Report is about the processes of IBCA, and the history of how it came to be set up as it is but it is about much more than that. The details explored in some of the chapters may on first reading seem technicalities that may be of interest to dedicated lawyers – but that would be to hide the potential for injustice which the practical effect of those details creates. It **matters** to those affected by the provisions in question. Fairness is critical.

If I were to pick the underlying themes which run through the evidence, the people, the hearings, and the need for improvement in a number of ways, they would not be matters of small detail. They would be large principles. The theme at the heart of what has been read, and heard, is giving people the dignity and respect they deserve. This means ensuring that people's voices can be listened to by involving them in the decisions that matter to them and avoiding being paternalistic and patronising. It means transparency as far as possible, so that people can understand (and if need be challenge, or secure change to) those decisions – for transparency and involvement go together. It means respecting a person's viewpoint. It means not just hearing but listening and acting. It is about truly valuing people so that people infected and affected are at the heart of things. Putting into practice these principles – the need for transparency, involvement, listening rather than simply hearing, recognising

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[744] This Inquiry's terms of reference include "*the nature, adequacy and timeliness of the response of Government*" and other bodies; and there is no provision that restricts the focus of the Inquiry to one particular time period.

(and remedying) injustice, truly valuing people – is a challenge for the here and now. These principles need to be not just matters of fine words, but together form a practical route-map to be followed.

Trust in government has only a tenuous hold; it was weakened further by the failures, recounted here, to give people the dignity and respect they deserve. That could have been achieved by involving them properly in establishing the processes by which they were to be compensated, and by involving them in helping to settle the detail of the scheme. The people who were infected know what happened to them far better than anyone else. They have the closest, most intimate knowledge and understanding of what people in a similar position have experienced. They could have been asked. But they still have that knowledge, and that understanding. It is still there to draw on, to help understand the practical effects of the way the scheme works. It is likely to be of central importance in determining how future claims (people never yet compensated, deceased infected, people affected) should be approached.

As Andrew Evans observed "*We are where we are*": this is not a moment to look back. It is the time now to build constructively on the scheme as it is, and as it operates. It is an opportunity to look forward. If the big principles which together give people the dignity and respect they deserve are honoured, then there should be no further need for any further hearing of this Inquiry, nor for any further Report. Some trust will be regained in government and public bodies. But more importantly still, people who have suffered most in the infected blood scandal should be able to feel that they have indeed (and finally) been put at the heart of things that matter.

I think that it is within reach that people infected and affected will be able to feel that they have, overall, been compensated fairly. The Inquiry has done what it can for now through its further hearings and this Additional Report – it has made recommendations. It is now for IBCA, and the Minister and the Government to take action, by putting those recommendations into effect, or being clear and transparent about why they cannot or should not be.

All sides of the House of Commons on 20 May 2024 were in agreement that "*we must fundamentally rebalance the system so that we finally address the pattern, so familiar from other inquiries such as Hillsborough, where innocent victims have to fight for decades just to be believed*", "*we must restore the sense that this a country that can rectify injustice*", "*We must now ensure that full compensation is paid without any more delay*", with thanks to people infected and affected "*for being able to pry open the doors of this place and ensure that your voices were heard by all of us.*" One former Health Secretary, though, asked "*why will it be any different this time?*"[745] Unfortunately as this Additional Report records, people infected and affected have not felt a marked change since 20 May 2024. But with the funding for compensation already in place and a renewed commitment to involve people so badly let down by the state and give proper respect to their experiences, it can be different. Truly

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[745] Hansard Rishi Sunak (then Prime Minister), Sir Keir Starmer (then Leader of the Opposition), Ed Davey (Liberal Democrats), Stephen Flynn (Scottish National Party) and Sir Sajid Javid speaking in the House of Commons debate on the Infected Blood Inquiry Report 20 May 2024 p2, p3, p5 RLIT0002476

involving people infected and affected in how the state recognises their losses would start to turn the page on the past.

Brian F.J. Langstaff

Sir Brian Langstaff
Chair, Infected Blood Inquiry
9 July 2025

ISBN 978-1-5286-5876-8
E03396011