

IN THE MATTER OF THE

INFECTED BLOOD INQUIRY

SUBMISSIONS MADE ON BEHALF OF THOSE REPRESENTED BY COLLINS SOLICITORS

Introduction

1. Since the publication of Sir Brian Langstaff's second interim report¹ on 5 April 2023, 47 bereaved spouses and partners registered with EIBSS have died.² Of those, 21 have died since the publication of the Inquiry's final report.³ A registered affected spouse/partner is, therefore, dying approximately every two weeks.
2. One can only imagine that the official figure would be higher were it to include numbers of infected people, affected people other than spouses/partners and unregistered victims of this tragedy who have died in the last two years. Sir Brian's first interim report left no doubt that:

*"... delay must be avoided. Time without redress is harmful. No time must be wasted in delivering that redress."*⁴

3. In the Inquiry's report of 20 May 2024, Sir Brian said: *"In the context of this Inquiry, perhaps beyond all other, it is unconscionable to allow a state of affairs to exist in which these fears [on the part of the infected blood community] are realised. I am satisfied that I must do what I properly can within my powers to try to ensure this does not happen."*⁵ At that time, almost one year ago to the day, Sir Brian anticipated that within twelve months he would be able to tell the

¹ INQY0000453

² This data is correct as at 12 May 2024 and provided under a Freedom of Information request to the NHS Business Authority, published online here: <https://opendata.nhsbsa.net/dataset/foi-02787>

³ *ibid.*

⁴ <https://www.infectedbloodinquiry.org.uk/reports/first-interim-report>

⁵ Inquiry Report, volume 1, p282, <https://www.infectedbloodinquiry.org.uk/reports/inquiry-report>

Minister that the Inquiry had fulfilled its terms of reference. Unfortunately, he was not able to do so.

4. It is entirely wrong that time and other precious resources have been wasted in delivering the redress so far. The process is still far from complete. Those infected and affected who wrote to the Inquiry raising their concerns, which led to the Inquiry convening hearings on 7th and 8th May 2025, were right to do so. Even before the hearings happened, the mere fact of their imminence seems to have prompted IBCA to act and to update the community that it intended to speed up the claims process.
5. The Core Participants represented by Collins Solicitors are extraordinarily grateful that the Inquiry continues to have regard to its Terms of Reference, and in particular paragraph 5, despite the Chair's hoped-for timetable not being realised. They are grateful that the Inquiry did not ignore the "*distress and feelings of powerlessness*"⁶ in their communications with it since 20 May 2024, in sharp contrast with the response of government.
6. The Inquiry has invited recommendations in light of the hearings, the evidence heard, and the material gathered.
7. These submissions do not seek to repeat the contents of CTI's presentation and chronology.⁷ We invite the Inquiry to re-read (and we adopt without repeating here) the recommendations set out in the witness statements of Danielle Holliday⁸ and Benjamin Harrison,⁹ together with the closing submissions submitted on behalf of Milners Solicitors' clients (which we have seen in draft and wholeheartedly endorse).
8. The focus of these submissions therefore is on additional practical matters to ameliorate the current intolerable situation, as the strong criticism of

⁶ Statement of Sir Brian Langstaff, 13 March 2025, published at <https://www.infectedbloodinquiry.org.uk/news/infected-blood-inquiry-publish-additional-report>

⁷ INQY0000463

⁸ WITN7763001

⁹ WITN7759001

government and its effect on the community cannot be better expressed than by the Panel who gave evidence on 7 May 2025.

Recommendations Relating to the Compensation Scheme

A. Submissions relating to the setting up of the Scheme

9. The Government's approach to setting up the IBCA amounted in effect to a rejection of the IBI's recommendations, in key ways, despite the ostensible acceptance. This undermined the trust of the infected and affected communities from the outset.
10. Sir Robert Francis's previous testimony to the IBI in 2022¹⁰ identified concerns regarding the lack of engagement and quality of engagement with the community.
11. Specifically, he wanted to avoid private panel discussions, coming back 6 months later with proposed solution, then a 6-week summer consultation to produce a result. He wanted real involvement to carry the trust of the people involved.¹¹
12. The Cabinet Office was aware of his comments,¹² and what to avoid. But it did not avoid what Sir Robert feared. It provided only 1 panel and a 3-week consultation process. No explanation was offered, and instead blame was attributed by the Cabinet Office to the Inquiry for late reporting and to Parliament for setting a deadline in the statute and having an election. This is untenable.
13. The Cabinet Office did not set up an independent arm's length body to report to Parliament. The Minister retained overall control, on the spurious basis of

¹⁰ INQY1000224 p36 §144/145

¹¹ Transcript 8 May 2025, p157 line 8.

¹² Transcript 8 May 2025, p158, lines 7-10

the likely scale of the scheme and sums involved. This approach was in fact a way to retain control and further the government's narrative.

14. Recommendation: There should be independence in the composition of the IBCA Board, and all its exchanges with the Minister should be published.

15. Mr Quinault states the Cabinet Office proposals were made in an attempt to repair trust with the community. He stated that the Cabinet Office will seek to do so by taking on board what the Inquiry says, and that they will take on board the points made about the scheme.¹³ In our submission, this statement made in a formal setting amounts to an undertaking.

16. The Cabinet Office appointed an Expert Group to advise them, which:

- a. was essentially anonymous, save for the Chair;
- b. did not comprise the specialisms advised by the IBI;
- c. did not include access to, or involvement with, the very community impacted by their actions and decisions. This was, according to the Chair of the Expert Group, excluded by their Terms of Reference;
- d. had civil servants attending the meetings of the Expert Group to take minutes of those meetings.

17. Appointing Browne Jacobson, an existing contracted legal firm to the government, as legal advisors was ill-advised. By dint of their pre-existing relationship, defending clinical negligence claims against the NHS, it is reasonably perceived by the community that their appointment encodes an attitude of saving the government money wherever possible. Browne Jacobson have no relationship with the community, and lack the appearance of independence.

¹³ Transcript 8 May 2025, p161 lines 13-19

B. Submissions relating to the operation of the scheme under the Infected Blood Compensation Scheme Regulations 2025 ('the Regulations')

Regulation 3: Meaning of 'eligible infected person' and HIV

18. Regulation 3(4)(a) sets out an eligibility period for HIV compensation which begins in 1982. It is not clear why this period appears in the Regulations when it did not appear in the recommendations, although an email from IBCA provides a purported 'legal basis for 1982 start date'.¹⁴ In his oral evidence, Mr Quinault stated this purported legal basis did not come from the Cabinet Office and that it was not reflective of the government's position.¹⁵ It is therefore hoped that the government is amenable to amending the Regulations. Mr Thomas-Symonds stated: "I am more than happy to go away and look at that situation. I can say today I am willing to."¹⁶

19. In his Third Statement, Mr Quinault said he believed the email had been written by IBCA staff.¹⁷ In oral evidence, Sir Robert Francis and David Foley concurred, suggesting it was an attempt by IBCA to understand the policy behind the Regulations.¹⁸ If IBCA have adopted a civil liability approach to 'date of knowledge', this is to misunderstand the basis of the Inquiry's recommendation which did not presuppose civil liability. It is apparent from the IBI findings that infection may have arisen before 1982, and pertinently, that if the government of the day had taken steps to minimise the risks of Hepatitis in the years before 1982, this was likely to have had a dramatic impact on the incidence of HIV. The Minister in oral evidence said that he understood the basis on which it is said that IBCA's approach was fundamentally flawed.¹⁹

¹⁴ DHOL0000003

¹⁵ Transcript 8 May 2025, p148, lines 13-15

¹⁶ Transcript 7 May 2025, p152 lines 17-18

¹⁷ WITN7755006, §56

¹⁸ Transcript 8 May 2025, p83-84

¹⁹ Transcript 7 May 2025, p152-153

20. It thus appears that IBCA's understanding of the Inquiry's findings leaves much to be desired. That this situation could have arisen is concerning, to say the least. However, IBCA's email also stated: "*We also acknowledge that campaigners are continuing to challenge these legal boundaries, and such challenges may, shape future decisions or legislative changes.*"²⁰ If this is a truthful statement then IBCA should be open to changing its position, particularly under the avowed 'test and learn' approach. IBCA should also be vigilant to ensure that fundamental misunderstandings do not arise, reviewing the training provided to case managers, their supervisors and the policy team if required.

21. Recommendation: Regulation 3 should be amended to remove the start date from the period, and simply refer to infections up to 1 November 1985. IBCA should reconsider their understanding of the basis of the Inquiry's recommendations and exercise vigilance to avoid fundamental misunderstandings arising in future. IBCA should be receptive to applicants pointing out misunderstandings.

22. It should not be assumed that the change will make no material difference. Many applications on behalf of those who died in the late 1980s from AIDS will lack medical records to ascertain dates of treatment with Factor concentrates. Even where records exist, they may only serve to disentitle deserving applicants. For example, a mild haemophiliac who was treated intermittently may not have received Factor concentrates within the period 1982-1985 and yet subsequently diagnosed with HIV. Collins Solicitors are aware of one such coinfecting case (which was accepted under IBSS but) which, under the Regulations, would be considered as a mono-infected HCV case.

²⁰ DHOL0000003 (emphasis added)

Assumptions made under the Regulations are inaccurate, and give unfair results

23. Mr Quinault agreed to review the 'deeming provisions' under Regulation 20(7), arising where there are no medical records or evidence to establish progression through the different levels of illness severity.²¹

- a. This presently takes the relevant date, as the date of application to the scheme and works backwards thereafter (for a period of 4 years for stage 4 at 100% and 6 years for stage 3 at 80%). This overlooks the duration of the period prior to stage 3 (at 40%) and or when stage 3 was in fact entered. This is unfair. Whilst he states²² these are *only* applied if there is no other evidence at all; he then states that, where there is a known liver transplant but it is unknown when progression of the disease occurred, they would nevertheless *still* take the date of application to the scheme as the relevant date. Furthermore, whilst Mr Quinault acknowledges this loss in his Third Statement²³, he states within the same sentence that this "is a significant sum, but it is small".
- b. He also accepted²⁴ there is an anomaly in that the regulations and deeming provisions cannot provide a middle ground as they do for an estate's claim. In oral evidence, he offered to provide a supplemental statement on this issue.²⁵ Mr Quinault's Third Statement, received on 22 May 2025, does not concede anything in this respect but rather simply reiterates his position (§§57-69).

24. Recommendation: The anomaly of the deeming provisions in Regulation 20(7) for financial loss (core) awards, should be amended to provide at least a middle ground (as in Estate claim calculations).

²¹ Transcript 8 May 2025, p152

²² Transcript 8 May 2025, p152

²³ WITN7755006 (§67)

²⁴ Transcript 8 May 2025, p153 lines 18-22

²⁵ Transcript 8 May 2025, p154 line 15

25. It is an admitted flaw in regulation 33(2)(a)(i) and (ii) which (as currently drafted) will not allow anyone infected with HIV as a child, who cannot point to any work they were doing before being diagnosed, to recover appropriate sums for financial losses. Mr Quinault stated in oral evidence that he is happy to clear this up. This is not addressed in his Third Witness Statement.

26. Regulation 33(4) regarding claims for exceptionally reduced earnings assumes applicants worked before being diagnosed with an infection.²⁶ It only covers an applicant if they were established in well remunerated job, and then developed HIV/AIDS so that they could no longer work. Mr Quinault stated claims managers are instructed to take the peak of someone's earnings. This is difficult for claims managers to undertake if there are no earnings, or earnings are so limited as to not be reflective of the lost potential.

27. Recommendation: Regulation 33 should be amended to consider the situation where it is not possible to provide 5-years previous earnings figures (for whatever reasons) with consideration given to alternative means of assessing exceptional reduced earnings (e.g. reference made to ASHE figures for specific likely careers).

28. In the case of an applicant born after 1961 and positive for HCV, Reg. 20 assumes (i) an applicant was effectively treated for HCV from 2016 onwards and (ii) the virus cleared, so that an applicant was able to work.²⁷ The Regulations significantly reduce the amount of compensation payable from that point.

29. These assumptions do not go hand in hand. Treating HCV does not reverse liver damage, or treat symptoms of chronic fatigue, brain fog or the accumulated physical toils of decades. Reducing compensation from that point does not reflect the true position, and is unfair as there may be no financial

²⁶ RLIT0002941 and Transcript 8 May 2025, p156

²⁷ Transcript 8 May 2025, p138 and p139 line 140

effect of treating HCV for individual applicants. For example, not all applicants will have increased earning capacity after treatment.

30. Core Participants have highlighted to Collins Solicitors their experiences of the impacts of early Interferon treatment, and their current frustration at their exclusion from accessing Supplemental Route and Special Category Mechanism payments, throughout the ongoing application processes. There is repeated anger at the lack of recognition of the devastating impact from such, and the impediments to compensation under core or supplemental route processes.

31. For example:

- a. Mr AE states: *"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."*
- b. Ms XX states: *"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 sub-route, as the health consequences of my autoimmune disease are so incredibly severe."

32. The reality is that there is no eligibility for most people under the supplemental route unless they have specific and rare health conditions.

33. In oral evidence, Mr Quinault was asked how the recognition of treatment with Interferon factored into the core awards.²⁸ His response to the question was simply that the broad tariff was intended to cover both those who were impacted by the treatment and those who were not.

34. One problem with this response, especially with level 2 HCV claims, is that it disincentives many from taking the lump sum payment. To do so does not make financial sense when the loss going forward is limited to £11,863 p/a (which in most cases falls to £5,931 from effective treatment date in 2017, and then halves again to £2,965.50 from age 66 to Healthy Life Expectancy). The IBSS Special Category Mechanism is usually at least twice the maximum per annum (and sometimes three times) and is guaranteed for life. The IBSS route therefore more closely reflects the impacts of Interferon.

35. Recommendation: Regulation 20 should be reviewed with a proper inquiry into the applicant's circumstances undertaken, rather than misguided assumptions of fitness to work. If still in receipt of support payments or benefits after 2016, there should be a presumption that

²⁸ Transcript 8 May 2025, p124

despite HCV clearance that applicant was still unable to work unless there is evidence to the contrary.

Special Category Mechanism ('SCM')

36. The Government seems determined not to simply adopt the previous SCM payment approach, instead adopting a more restrictive 'Severe Health Award' eligibility, for example, introducing a need to identify a diagnosed psychiatric illness with inpatient admission to hospital or extended Consultant treatment (6 months), to qualify for a Severe Health award following Interferon treatment.
37. This is misguided and unfair. It sets the bar too high and fails to recognise other long-term effects falling short of such a high bar, such as brain fog and most common psychological or psychiatric effects. The new 'Severe Health Condition' payment route is for rarer impacts not already covered by the core award. Eligibility is based on clinical markers which applicants should be able to provide specific evidence of.
38. Mr Quinault agreed that if the boundary has been set where no-one can meet the test because of their conditions at that time, this would be reviewed.²⁹
39. At present, the requirements do not assist those who were registered and in receipt of SCM payments, as (contrary to assertions of continuity and not being worse off) a new criterion is now being applied, for a different payment, leaving them potentially unable to satisfy such and therefore being out of pocket or worse off.
40. The Regulations are said to be open also to unregistered claimants who have not been assessed for SCM. Previously unregistered applicants will also face hurdles of providing medical records, where such have been lost, destroyed or are otherwise unavailable.

²⁹ Transcript 8 May 2025, p136, lines 11-15

41. **Recommendation:** The Regulations should be amended to extend the categories of eligibility for Severe Health Awards, so as to reflect the previous Special Category Mechanism route (taking a favourable interpretation of the slight nuances between Scottish and English versions).

Where there is doubt or uncertainty from an absence of medical records, there should be a presumption of eligibility *unless* there is evidence to the contrary within the records available, at which point a holistic view should be adopted, with the emphasis on inclusion rather than exclusion in borderline cases.

Furthermore, previous recipients of SCM payments should not be financially worse off after any Severe Health Award assessment. Their previous payments should act as a minimum sum payable by the IBCA, with guidance given in those specific terms to all claims managers.

IBSS cut-off date

42. The IBSS cut-off date of 31st March 2025 after which spouses / partners receive no support payments must be reviewed. Mr Quinault's second witness statement stated that an infected person can provide for their partner from their own compensation.³⁰ In evidence Mr Quinault agreed³¹ that this assumes they have received their compensation and that a person who received support payments effectively as a couple might suddenly have them cut off, on the premise that the infected person had received their compensation prior to demise to leave it to their partner.

43. **Recommendation:** The Regulations should be amended to provide for support payments to continue until agreed compensation has been paid.

³⁰ WITN7755003, p34 §213

³¹ Transcript 8 May 2025, p145, lines 13-16 and p144, line 5 generally.

44. Mr Quinault agreed³² that whilst there is provision in the Regulations for co-infection uplifts (with HCV & HBV and HIV & Hepatitis), there is none for triple infection – HIV, HCV & HBV.

45. The IBCA has set a ceiling for co-infection compensation that does not acknowledge the possibility of triple infections and the additional suffering and consequences thereof.

46. Recommendation: Provision should be made for the occurrence of triple infections with additional sums payable above the current maximum for co-infections.

The Regulations make no provision for 'supplementary route' payments to the affected, only the infected. This is unfair and unjust.

47. Mr Quinault agreed³³ that the scheme is intended to compensate affected people for their own suffering as a consequence of this scandal (i.e. complex childhood grief, interrupted development in education, long term mental health issues).

48. He also agreed that the tariff does not cover every individual circumstance, and did not provide a supplementary route for the affected on the basis that: (i) it would have to cover a very wide group of circumstances; and (ii) If they introduced a discretion this would lead to further delay.³⁴

49. This is misguided. 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.

³² Transcript 8 May 2025, p146 line 7

³³ Transcript 8 May 2025, p136 line 7

³⁴ Transcript 8 May 2025, p137, line 22

50. To deny this logic, on the basis it is too wide or would delay matters, misses the point and does not reflect the fact it is a 'supplemental' payment for additional experiences. Taking a little longer to get a fair and just decision is the right thing to do.

51. Recommendation: The affected should be eligible for 'supplementary route' payments in the same manner that the infected are, with criteria drawn up to reflect any additional suffering experienced, especially where educational, occupational and psychological aspects have been adversely impacted beyond the 'normal' anticipated experiences covered by the core award.

Scope of the unethical research award

52. The scope of the unethical research award is plainly more limited than anticipated by the Inquiry's recommendations. For example, it is limited in the number of centres it covers (even though the Inquiry was expressly not prescriptive in its final report), in the amount of the award, and in the absence of discretion for IBCA to make the award other than prescribed by the Regulations.

53. In relation to discretion, Mr Foley's oral evidence could be interpreted as suggesting that IBCA does at present have discretion under the scheme.³⁵ However, this certainly is not the experience of applicants to date.³⁶ The Minister stated that he was "*more than happy to look at*" granting IBCA such a power.³⁷

54. This is cautiously welcomed. The caution arises because Collins Solicitors wrote to the Cabinet Office on 10 December 2024 commenting on a Fact Sheet circulated about unethical research awards. Specifically in relation to

³⁵ It is not clear whether this is advanced as a hypothetical example about what *could* be provided in Regulations but is not in fact provided: Transcript 8 May 2025, p169

³⁶ Transcript 7 May 2025, page 40 line 13, page 86 line 11, page 91 line 7

³⁷ Transcript 7 May 2025, page 170 line 12

Treloars, the period in which unethical research was carried out was significantly longer than the Fact Sheet provided for. A response by letter of 23 December 2024 simply stated that an ongoing engagement process was underway and that the Minister would provide an update in due course.

55. In light of this response, we echo the words of Sir Brian Langstaff to the Minister at the closing of his evidence: *"You [say you] would be happy to look again at giving IBCA the power to accept claims for supplementary payments on unethical research on a one-by-one basis. You have given all those assurances to us. I hope and feel sure that you must realise that you have, by those undertakings, given hope to those people who are here listening to what you have to say and that you are aware when you leave today that you will have the trust of this community in your hands and it would be in part by what you consider the right answer should be whether that trust is acknowledged as rebuilt so far as they are concerned or jettisoned on the other hand."*³⁸

56. As to the amount of the award, the Minister, in oral evidence, was urged on behalf of CPs to consider the amount of the award.³⁹ He elsewhere stated that he had made changes to this award but would always be driven by a consideration of avoiding delay.⁴⁰ However, he later accepted that delay would not be caused in this instance. *"I'm not ruling out -- I've made the unethical research award example -- changes you could make without causing delay and without causing that sort of fundamental difference that would lead to a delay in payments."*⁴¹

57. The Minister had previously given a Written Answer in Parliament, which was confirmed in his oral evidence, that further centres could be added by way of secondary legislation.⁴² This need not lead to delay. Any offers that have been accepted to date which ought to have received unethical research awards

³⁸ Transcript 7 May 2025, page 196

³⁹ Transcript 7 May 2025, p168-169

⁴⁰ Transcript 7 May 2025, p107 line 8; see also p121 line 12

⁴¹ Transcript 7 May 2025, p127; see also p121 line 12

⁴² Transcript 7 May 2025, p169

should be “topped up” to match their entitlement made by any future secondary legislation.

58. The Minister accepted that there had been limited consultation on this topic, but justified his actions by saying that he felt the voices of victims were “on his desk”⁴³ (presumably on paper). This is weak. It was therefore appropriately conceded that changes could and should be made.

59. Recommendation: The scope of the unethical research award should be widened by secondary legislation. IBCA should be granted discretion under the Regulations to go outwith any limitations inherent in the drafting of the Regulations (for example, as to centres, dates, or amounts of the award).

Core and Supplementary Financial Loss Calculations

60. Reference is made to the submissions on behalf of Milners Solicitors (paragraph 16 onwards); Ben Harrison’s Witness Statement paragraphs 91-116 (complaint) and 117-212 (recommendations) and Danielle Holliday’s Witness Statement, paragraph 123.⁴⁴ There have been several written requests to Mr Foley seeking clarification of financial calculations and questions of past loss. Responses date have been unsatisfactory, simply stating that “those are the Regulations”.

61. Collins Solicitors have also previously identified that the formulas used in the calculations serve to only significantly reduce past losses, for those who elected to accept a smaller annual lump sum and continue with support payments. This is at odds with IBCA/Cabinet Office statements made, that any election to keep support payments will only affect future loss.

⁴³ Transcript 7 May 2025, p118 line 3

⁴⁴ WITN7763001

62. The Regulations and their calculations are opaque and not easily comprehensible. Several applicants and lawyers have expressed the view that “nobody can make head nor tail of it”.
63. There seem to be anomalies in the way in which the formulae in the Regulations operate. The overarching framework seems to be that the core award for financial loss will apply, so long as it is not exceeded by the supplementary amount, in which case the latter will apply.
64. There is therefore interest in examining what the circumstances of an infected person (‘P’) must be, for the supplementary calculation to apply. This is seen in a hypothetical test case of ‘P’ with a double infection, covered by Reg.20(4)(a) and ‘P’ with a single infection under reg.20(4)(b). With all other factors assumed to be the same, e.g. all key dates, and the salary level of P, (which is assumed as around the 90 percentile level, at which point some supplement should be reasonably expected). Further it is assumed that both infection and diagnosis occur before the age of 16.
65. In the doubly infected case, the core award is fixed at £29,657 p.a. and applies from the age of 16, a large total is accumulated before the date at which the supplementary calculation commences (i.e. the start of the “reduced earnings” period). The following is noted:
- a. It seems anomalous that the supplementary calculation does not recognise any financial loss prior to the reduction in earnings, whereas the core calculation does. (This is true for both singly and doubly infected persons).
 - b. In the supplementary calculation for doubly infected P, by the retirement age of 65 the cumulative loss figures for the core and the supplementary calculations are almost the same. By age 85, however, the supplementary calculation falls well below the core calculation because the latter continues at 50% of £29,657 (i.e. £14,829) whereas the supplementary calculation continues at a much lower rate (£5,976).

The overall effect is that, for a doubly infected P whose final earnings were at the 90 percentile level, the supplementary calculation adds nothing to their award. This seems fundamentally wrong.

66. For the singly infected P, the core award is fixed at £18,536 and the cumulative core total is lower by about £650,000; hence the supplementary calculation beats the core, and would add roughly £500,000.

67. It also seems anomalous that the threshold for supplementary award contributing should be different for different diagnoses, when the salary level is the same at 90 percentile. Further, for doubly infected P at lower final salary levels, the supplementary calculation would not kick in.

68. For a singly infected P, the supplementary calculation would become active if the final salary were somewhere around the 65-70 percentile level.

69. Finally, it must be mentioned that the calculation of the annual loss of income for the years after age 65 is a formula based on the employee's annual pension contributions. It is not an actuarial calculation of the pension payout, that should have resulted from the prior years of missed employment and pension accumulation. Furthermore, it does not appear to recognise the loss of the employer's contribution. This results in the annual amounts in the supplementary calculation being very low for the period between age 65 and age 85.

70. Thus, this is a scheme that will inevitably generate significant anomalies in the distribution of compensation between different claimants.

71. Recommendation: the anomalies between the core and supplementary routes, and between mono-infected and coinfecting Ps should be eradicated. The formula should be simplified to the greatest extent possible whilst conserving the justice of the outcome.

Approach to absent or sparse medical records

72. Turning more generally to cases of absent or sparse medical records, incomplete and/or inconsistent medical records are at present held against applicants by IBCA, contrary to recommendations, when the explanation for this state of affairs was set out at length in the Inquiry's final report. In Mr Foley's evidence, he stated that IBCA used a balance of probabilities test in the absence of evidence but also used knowledge of other applicants under the test and learn scheme.⁴⁵ Sir Robert Francis added: "*We are fully aware of the fact it's not just about medical records or a signed piece of paper, it's about people's recollections and so on. Obviously it is -- and I should say behind that is also our philosophy which is to be supportive towards people, rather than to make negative presumptions.*"⁴⁶

73. However, this view is belied by the experience of applicants. One example of this problem arising is, in the experience of Collins Solicitors, the evidence taken into account by IBCA when deciding on severity levels of Hepatitis where medical records are incomplete/inconclusive. Determinations of severity levels have particularly disparate impact in applications for mono-infection with Hepatitis or coinfection with HIV and HBV.

74. In the case of an applicant who was diagnosed only in 2021 with HCV but had had the infection for decades before 2021 and was in receipt of Stage 2 EIBSS payments, a claims manager was not open to the assertion that cirrhosis began before the diagnosis in 2021. Most chronic liver disease is asymptomatic until decompensated cirrhosis develops. Logic dictates that the client would have been cirrhotic before it was diagnosed and yet medical records identifying potential symptoms (indicators) of cirrhosis in the preceding years were not accepted as sufficient evidence of levels of severity. Nor was IBCA open to the submission of publicly-available peer-reviewed scientific

⁴⁵ Transcript 8 May 2025, p34: "*Obviously, for all of the reasons that the Inquiry found, in many cases records are patchy or are non-existent and that is the point at which we move to the balance of proof.*"

⁴⁶ Transcript 8 May 2025, p36

articles to explain the significance of entries in the medical records. The only acceptable evidence would appear to be an entry in the medical records that stated 'cirrhosis'.

75. In another case, concerning IBCA's interpretation of whether an applicant suffers from cirrhosis, the applicant has suggested that IBCA should approach medical evidence in a different way. Rather than asking, in borderline cases, whether the evidence confirms cirrhosis, IBCA should ask whether the evidence excludes cirrhosis. *"Having had time to reflect, [...] I believe that [...] IBCA are asking the wrong question. Rather than asking 'does this biopsy indicate cirrhosis?' perhaps you should be asking 'does this biopsy rule out cirrhosis?'. This is particularly pertinent in the situation where medical records have been deleted, and methods of recording and measuring fibrosis have changed."*

76. Recommendation: Claims managers should take into account other available evidence such as the Inquiry witness statements, reports of treating clinicians or independent medical reports, or evidence of illness in employee occupational health records. Decisions should be made on the balance of probability weighted in favour of the claimant in borderline cases.

77. We adopt the submissions of Milners Solicitors as to the proper interpretation of Schedule 1 to the Regulations and the definitions for each level of severity of hepatitis infection (§§63-74).

78. In the experience of Collins Solicitors, the kPa score is used by claims managers as the only clinical markers of cirrhosis and as a definitive scale. However, a kPa score can be inaccurate and, in any event, bears no obvious relation to the legal definition under the Regulations.

79. The clinical scoring system is conventionally categorised into stages (F0-F4) which are being conflated at IBCA with the levels provided for in the

Regulations. Different scoring systems, like NAFLD Fibrosis Score (NFS) and FIB-4, use blood tests alongside clinical data and other symptomology to assess fibrosis.

Inheritance tax for secondary transfers of compensation and other complications

80. As raised in the Law Gazette,⁴⁷ the exception for payment of inheritance tax does not benefit secondary transfers of the compensation (or any subsequent transfer).

81. The Tainted Blood group have written to the Prime Minister to, inter alia, notify him that compensation paid to estates may be entailed away in some cases from those who have suffered the most. They have recommended that IBCA provide support and arbitration to ensure that estate claims are paid to those most impacted by someone's infection and death.

82. Collins Solicitors are aware of one particular case of a widow who has been twice affected by the Infected Blood scandal because she married two haemophiliacs.

- a. LN was married to ZE for 28 years. Together, they had three children. After ZE's passing, LN later remarried a person (FP) who also sadly passed away. Both ZE and FP's Wills name LN as the primary beneficiary, and her children as the secondary beneficiaries of their estates. However, due to the significant delay in the payment of compensation, this structure is now causing serious and unforeseen financial consequences, particularly in relation to inheritance tax. The family believes that ZE's Will, which was made around the time of the *ex gratia* payment, does not reflect his wishes. They believe that had he survived until now and understood the financial implications, he would have structured his Will entirely differently to prevent any unnecessary inheritance tax liability. Due to the passage of time, LN has lost her right to make use of a Deed of Variation which has

⁴⁷ <https://www.lawgazette.co.uk/news/infected-blood-families-falling-into-inheritance-tax-cracks/5123213.article>

prevented her from ensuring that ZE's compensation is passed down wholly and immediately at the time of distribution—free from inheritance tax. The family (including LN) believe that the compensation should be paid directly to the children and not to the named beneficiary in his Will, but there is currently no provision to be able to use a Deed of Variation which must be completed within two years of the date of death. The same issues arise with LN's second husband given the passage of time and inability to make use of a Deed of Variation.

- b. Should LN pass away before compensation is paid to either estate, both sets of compensation will be subject to inheritance tax as secondary transfers.

83. Recommendation: Legislation should be passed to avoid inheritance tax upon secondary (or any subsequent) transfers and to suspend the time limits for deeds of variation. Time should run from date of payment of compensation to the infected deceased. Further, IBCA should provide support and arbitration to ensure that estate claims are paid to the person most impacted by someone's infection and death.

IBCA "clinical assessors"

84. At present, IBCA has only one clinical assessor. Neither Mr Foley nor Sir Robert Francis confirmed what her clinical specialty was in their oral evidence.⁴⁸ This clinical assessor has decided on claims and her qualifications are unknown. However, it is believed she was previously advising IBSS. There is a lack of transparency in decision-making. Neither she nor any clinical assessor is currently required to provide reasons for their decision. A lack of trust in the process has therefore arisen amongst applicants.

85. Recommendation: All clinical assessors to whom a request is made by the claims manager should be named and their specialty identified when

⁴⁸ Transcript 8 May 2025, pp19-20

their input is sought by claims managers. Questions concerning Hepatitis should only be decided by suitably qualified hepatologists and not a generalist. A description of the role of the clinical assessor and the range of expertise that the clinical assessors have should be put on the website. Clinical assessors should consider claims on the balance of probability, not scientific certainty, and the balance should be weighted in favour of the claimant absent any evidence to the contrary.

86. As there is only one clinical assessor, claims managers previously informed Collins Solicitors that there is a 4-5 week delay while response to questions from clinical assessors are awaited. However, subsequently, at a meeting attended by Collins Solicitors on 21 May 2025, Mr Foley confirmed that they have appointed a medical agency and will have access to 50 new clinical assessors. This, in our submission, is evidence of the rapid pace of advancement spurred by the Inquiry hearings.

87. The practice of IBCA at present is to consult clinical assessors via an online meeting or text-based chat stream. This practice does not lend itself to transparency and the provision of reasons which are accessible to applicants.

88. Recommendation: In light of the undesirability of further delay, the advice of clinical assessors should not be sought unless it is truly necessary (e.g. where matters cannot be dealt with on the burden of proof). All questions asked by the claims managers and any decision by an assessor to reject applicants' evidence should be set out clearly in writing, with reasons. This will ensure transparency and help to restore the trust of the community.

IBCA's approach to the interpretation of the Regulations and its remit generally

89. The foregoing paragraphs have, in various ways, identified discrete issues arising from inflexibility in the drafting of the Regulations – for example: the HIV eligibility window, the requirement to have evidence of co-infection with

HBV for at least 6 months, unethical research at regulation 26 which is prescriptive both on dates and locations, etc.

90. The Minister, in oral evidence, appeared to operate under a presumption that IBCA could take a purposive interpretation of the Regulations. For example, in relation to the HIV eligibility window, he said: *“That is the liability window where if you show the infection in that window and in the date then there's an automaticity to it, but my understanding is if there was an infection before that date the automaticity isn't there but there's greater evidence requirements in terms of showing in that period.”*⁴⁹ CTI pointed out that this was not expressly provided for in the Regulations, and the Minister then undertook to consider the question further.⁵⁰

91. The inflexibility in drafting of the Regulations is compounded by IBCA adopting rigid policy documents and/or “Fact Sheets” which limit the Regulations further.

92. For example, one claims manager wrote to Collins Solicitors saying that he has *“been reading through [IBCA] policy guidance and speaking with contacts within our policy team regarding Hepatitis B and how we can evidence as the policy is strict”*.

93. A copy of the guidance itself was only provided to RLRs after the Inquiry hearings. We observe that this is likely to have been an indirect result of Inquiry scrutiny.

94. The policy states that *“We consider a person to have evidence that shows they have chronic hepatitis B if: • they have had 2 positive HBsAg (surface antigen) tests more than 6 months apart, with detectable hepatitis B virus DNA on a PCR test, • they were infected when they were 5 years old or under and had a positive hepatitis B test, • they have been treated for hepatitis B.”* These specific requirements are not stated within the Regulations.

⁴⁹ Transcript 7 May 2025, p151

⁵⁰ Transcript 7 May 2025, p151-152

95. Claims managers are directed to contact supervisors if this evidence is not supplied but the applicant considers themselves to have chronic HBV. The ultimate decision appears to rest with the policy team according to the document.
96. Still further, there is inconsistency of practice across claims managers. Some require specific items of evidence that are not required either by the Regulations or by other claims managers. There is a clear risk of inconsistent decision-making between applications either as to a claim manager's referral to their supervisors, or as to decisions made by the policy team. It is not clear whether symptoms of HBV such as jaundice will be taken into account.
97. Collins Solicitors are aware of at least one case where two applicants with HBV have been differentially treated. In the case of A, the claims manager has stated IBCA require "a positive surface antigen test" in a case where that test was not possible at the date of diagnosis. Other claims managers have taken evidence from the notes without a specific test. The latter is the right approach when testing and medical evidence were variably available through the period in question.
98. **Recommendation: All the regulations should be purposively interpreted in light of the Inquiry Report and Recommendations. Policy documents and fact sheets should not be more restrictive than the Regulations. Inconsistency between applications should be avoided.**

Sensitivity of the Scheme to individual experience

99. There is a more general issue that arises, which is the question of how sensitive to individual circumstances the Compensation Scheme should be. Flexibility of approach to evidence and purposive interpretation of the Regulations permits the scheme to be more finely calibrated to individual circumstances, whereas inflexibility tends toward a tariff-style scheme. This is

a tension the Chair was keenly aware of, and his recommendations came to a fair balance.

100. However, the Regulations and IBCA's website/policy documents indicates this tension is not resolved in the Scheme as enacted. Thus in a government document dated 21 May 2024 both individual circumstances and formulae or typical patterns are mentioned: 'CARE AWARD: The award is dependent on individual circumstances, and calculated against a formula based on the typical pattern of care needs for each infection severity band.' Further, 'FINANCIAL LOSS AWARD: The award is dependent on individual circumstances and is calculated against a formula based on the likely impact of an infection and subsequent treatment on an infected person's ability to work through disease progression.'

101. Applicants were under the impression that, in order to assess the amount of compensation, IBCA would take into account the immensely varied personal circumstances of the infected and affected. This was implicit in Sir Brian's recommendations, it was the rationale behind consultation, and implicit in the opportunity to relay their experiences to IBCA while making a claim. A government document dated 31 March 2025 states: "*The Government recognises the individuality of the experience of all those impacted by infected blood.*" However, this is manifested in words rather than actions. The approach is defended on the basis that it avoids intrusive questioning and re-traumatisation. However, it is experienced by applicants as a silencing and failure to properly understand the effects of their experiences.

102. Although David Foley's 14 May 2025 update states: "*They [claims managers] will work with you to gather all the information needed, so that the right level of compensation is paid as quickly as possible,*" applicants report that the focus of claims managers is much narrower, condensing around clinical criteria such as duration of infection and severity of liver damage. These criteria tend to aggregate applicants into bands rather than recognise individual experience.

103. **Recommendation: IBCA's approach should be tailored to the applicant's preferences and individual experience. IBCA should not avoid asking an applicant about their experience unless the applicant informs them that they do not wish to be asked.**

Applicants' interactions with claims managers

104. IBCA claims managers can be experienced by some applicants as wolves in sheep's clothing. They encourage applicants to trust them but do not advise them on their right to free legal advice. Collins Solicitors have been approached by clients who had signed declaration forms without solicitors' involvement. IBCA had generated an offer letter with an undervalue -- in one case by nearly £50,000 and in the other case by nearly £400,000.

105. **Recommendation: Claims managers should volunteer the information that applicants are entitled to free legal advice.**

Recommendations Other Than Compensation

Proposed prioritisation criteria

106. The cohort represented by Collins Solicitors have submitted individual views toward the Inquiry's proposed prioritisation criteria dated 13 May 2025, which we append. It has not been possible to summarise those views, so they are appended in their totality.
107. However, one common theme that can be discerned is that infected claims (living and deceased) should be prioritised. In this way, those who personally suffered will have their suffering recognised and affected people who are elderly – such as parents or partners/spouses – will receive the compensation due to the estate in short order, even if not the compensation due to them in their own right.

108. Whatever system of priority is adopted, our submission is that the involvement of RLRs in the preparation of claims could radically increase the rapidity of processing claims, due to the RLRs' extant familiarity with the documentation and the release of pressure upon IBCA case managers.

Language

109. **A recommendation that IBCA desist from referring to estate claims as 'affected'. Instead, IBCA should refer to 'infected deceased' claims.** As we said in our written and oral closing submissions in 2023, language matters. An analogy can be made with mesothelioma claims, which are conventionally distinguished between 'living' and 'fatal' claims. 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.

Psychological Support

110. *Infected Blood Psychology Service:* a recommendation that this be fully operationalised with all due speed and without further delay.

Memorial

111. *Memorial:* a recommendation that further steps be taken without delay toward implementing the Inquiry's recommendation 2 as to a national memorial.⁵¹

⁵¹ Inquiry report, p222

Implications of Accepting these Recommendations

112. On 14 May 2025, the Minister stated in the House of Commons: “*The inquiry has set out its intention to publish a further report, and the Government remain committed to co-operating with the inquiry and acting on its recommendations.*”⁵² He can only have been all too aware of the Chair’s parting words to him, which were:

You have also, I think, given us evidence of two things or two issues, the first relating to the design of the scheme, the second relating to the process. As to process, you have made it clear in your evidence, as I understood it, that you are ready to support going forward in terms of what is required to speed up the process and, in the same vein, that you are very conscious of the need for speed. You have said that if as far as the design of the scheme is concerned, that provided there is no significant delay to the payment, you will be prepared to consider the design of the scheme, in particular, as I understood you to say, in respect of the question of whether widows and widowers might continue to have the support of the support schemes, that you would look at the question of whether there should be a supplementary route by which children, parents and siblings could obtain further compensation. You will be happy to look again at the question of whether there is a cut-off date in terms of the HIV infection of 1 January 1982, you would look at the question of whether the SCM scheme should be revisited with a view to ensuring there is no anomaly there, and you would be happy to look again at giving IBCA the power to accept claims for supplementary payments on unethical research on a one-by-one basis. You have given all those assurances to us. I hope and feel sure that you must realise that you have, by those undertakings, given hope to those people who are here listening to what you have to say and that you are aware when you leave today that you will have the trust of this community in your hands and it would be in part by what you consider the right answer should be whether that

⁵² Hansard vol 767, col 380 (14 May 2025)

*trust is acknowledged as rebuilt so far as they are concerned or jettisoned on the other hand.*⁵³

113. Implementing the Inquiry's recommendations – both the ones outlined above and any further recommendations yet to be made – may well require the passage of secondary legislation. As the Minister conceded in respect of adding centres to qualify for the unethical research award, this is unlikely to cause undue delay. The Regulations have already been revoked and replaced once, the 2024 Regulations having been replaced by the 2025 Regulations.

114. Further, if consultation is genuine, the Minister should refrain from fettering his discretion to amend any relevant legislation in future. Although he stated in Parliament that IBCA's 'test and learn' approach is at an end, there can be no reasoned objection to further learning where it is merited.

115. In any 'test and learn' situation, there is a question about what learning is taken away. The Minister said in oral evidence: *"I also have in my mind experience of previous Government compensation schemes. I guess an example would be the miners' compensation scheme when the debate many years later was not about the victims received but the amount of money that lawyers received. [...] It's just a general point about learning from previous compensation schemes."*⁵⁴ While the general point is apposite, the example is misplaced. The learning that is a prerequisite to the administration of a just compensation scheme is the history of the infected blood scandal and, in particular, the community's experience of the Alliance House Organisations and IBSS.⁵⁵ Even to a well-intentioned learner, attention to the detail of the Inquiry report and the evidence that informed it is a prerequisite.

116. We endorse the submission made by Milners Solicitors that there ought to be a mechanism for internal review to cover shortfalls (whether due to

⁵³ Transcript 7 May 2025, pp 195-196

⁵⁴ Transcript 7 May 2025, page 172

⁵⁵ To a lesser extent, lessons can be learned from the Thalidomide Trust and even the 9/11 Victims Compensation Fund.

miscalculation in the award due to a claimant or a change in the Regulations) that is not by way of appeal (submissions §§ 166-167). In our further submission, the internal review should be available to applicants whose offers were accepted without the benefit of legal advice.

Conclusion

117. Taken as a whole, the differences between the recommendations and the IBCS, as enacted and operationalised, suggest that the scheme is operating with more exclusions than anticipated, higher evidential burdens for applicants, lower total sums by way of award, and significantly greater delays. The net effect of these differences is to compound injustices already suffered by this community.

118. The justifications offered by State witnesses in oral evidence for these differences were incoherent or unpersuasive. The evidence overall suggested that the discrepancies arose not due to a serious sense of fiscal responsibility but due to a more basic desire to reduce the cost of the scheme.

119. The Scheme as enacted represents something greatly less than the infected and affected were led to expect on Report Day by the promises of an outgoing government to pay 'whatever it cost'⁵⁶ and the moral indignation of an opposition who pressed for the amendment to what became the Victims and Prisoners Act, the enabling legislation for this scheme.

120. The sincerity of expressed moral commitments is tested when the speaker is compelled to undertake a cost as a result of that utterance. This government has shied from undertaking the cost associated with its expressed sentiments. The Compensation Scheme, as currently enacted, has eroded all the trust in government which was built up by the apology and acceptance of

⁵⁶ RLIT0002476; see also RLIT0002489, WITN2287088 pages 3-4, RLIT0002490 p29.

the moral case for compensation.⁵⁷ The State is now required to put its money where its mouth is.

121. As a letter dated 20 May 2025 from the Haemophilia Societies of England, Wales and Northern Ireland and Tainted Blood to the Prime Minister stated:

“A year ago today, as Leader of the Opposition, you apologised to those infected and affected by the contaminated blood scandal and told them: ‘Politics itself has failed you.’ Twelve months on from the publication of the Infected Blood Inquiry’s devastating report, there remains deep concern from the contaminated blood community that politics is continuing to fail them. [...] On 7 May the government made a public commitment to the Infected Blood Inquiry that it would review aspects of the compensation framework. We are keen for that to happen as soon as possible with full involvement of people infected and affected by contaminated blood products.”

122. In the Inquiry report of 20 May 2024, Sir Brian said he would notify the Minister that the Inquiry had fulfilled its terms of reference only if he was *“satisfied that there is no further role [he could] usefully play in preventing delay.”*⁵⁸ It is clear that the Inquiry, by holding hearings on 7 and 8 May 2025 and announcing an intention to report further, has already played a useful role.

123. Events have moved quicker since the Inquiry reconvened than they previously did, both at IBCA and within government. For example, an IBCA Community Update dated 1 May 2025 stated that *“we are increasing numbers as quickly as we can. We asked 200 more people to claim during the week starting 21 April and intend to ask 200 more next week (the week starting 5 May). From then on, we’ll ask an average of 100 people to start their claims every week, and in some weeks this will be higher as more claims managers*

⁵⁷ COLL0000022

⁵⁸ Inquiry Report, volume 1, p282, <https://www.infectedbloodinquiry.org.uk/reports/inquiry-report>

come on board." As to government, rule 9 statements and documents have been disclosed even since the evidence sessions.

124. We thank the Inquiry for the impetus it has provided. We hope that this momentum will be maintained of its own accord. And we hope that if it is not, the Inquiry will be responsive to any further concerns expressed to it.

Steven Snowden KC

Brian Cummins

Achas Burin

23 May 2025