

SUBMISSIONS ON BEHALF OF LEIGH DAY CORE PARTICIPANTS

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Introduction

1. These submissions are made to assist the Inquiry following the hearings of 7 and 8 May. They focus on the practical steps needed to restore confidence in the Infected Blood Compensation Scheme (the 'Scheme') and to place it on a stable and effective footing.
2. This document has two parts. The first addresses failures in the establishment of the Scheme and proposes a method for reviewing and consulting on the Scheme to ensure rapid and improved implementation. The second part summarises practical measures for the Inquiry to consider and adopt as recommendations across a range of issues, including prioritisation of claims, the treatment of particular groups, alongside several other matters.
3. The document highlights the need for transparency, accountability, and sustained engagement with the infected blood community and their legal and support group representatives. It also suggests targeted recommendations to support the Inquiry's reporting on how the situation can be improved.

Part 1: Addressing procedural failures and setting a path to reform

4. The Inquiry knows of the delays, lack of consultation, and absence of transparency that characterised the establishment of the Scheme — failings that led directly to the requirement for the hearing on 7 and 8 May. We do not repeat that history here. These submissions look forward. They focus on the practical steps now needed to restore confidence in the Scheme, and those administering it, and place the Infected Blood Compensation Authority ('IBCA') on a stable and effective footing that is capable of completing its task as soon as reasonable thoroughness allows.
5. That said, we trust the Inquiry will fully assess the background when reporting, in order that the course can be corrected. To support that analysis, we offer a broad overview and targeted recommendations in this Part.

6. The process by which the Scheme has been established has been marked by delay, opacity, and exclusion. Despite repeated calls for urgency, there were significant delays in setting up the Scheme. Those most directly impacted — infected and affected individuals — were not meaningfully involved in its design. Lawyers acting for these groups were effectively excluded from key stages. These are not procedural footnotes. They are central to whether the process has met the standards of fairness, transparency, and participation that this Inquiry had recognised¹ as being essential for an effective compensation scheme.
7. When the Scheme was determined, consultation was neither structured nor sufficient. Opportunities to contribute were limited, and when they did arise, they were tokenistic; a tick box exercise. There was no appropriate mechanism for gathering views, no transparency about how or if those views were considered, and no feedback loop to explain how decisions were made. The exclusion of the legal representatives who acted for many in the community during the Inquiry, meant that fundamental legal concerns were not addressed at the outset. The result was a process that lacked transparency, legitimacy and rigour.
8. The Infected Blood Inquiry Response Expert Group (the ‘Expert Group’), which was presented as a key step in progressing the Scheme, failed to inspire confidence, and instead for many eroded the little faith they had in the government fulfilling its commitment of paying compensation “whatever it costs”.² Its membership was appointed “in secret”,³ and did not reflect the breadth of experience or representation that the circumstances demanded. There was no open process for selection, and no explanation of the criteria applied. Engagement with stakeholders was limited and not appropriately broad, and the Expert Group’s work was conducted entirely behind closed doors. The Terms of Reference did not permit the Expert Group to take evidence directly from members of the infected community. The absence of openness, accountability and

¹ INQY0000453

² LDOW0000365

³ WITN0912009_0011, §40; members of the Expert Group were not revealed until the Infected Blood Inquiry Response Expert Group Interim Report was published on 28 May 2024.

the lack of involvement of the infected and affected undermined trust and confidence in the Expert Group's independence and purpose.

9. The status and role of IBCA remains unclear to many. There has been persistent uncertainty as to whether IBCA is operating independently of government. This is not merely a technical question. Independence is essential if the Scheme is to command the confidence of those it is intended to serve.
10. To address the position, we respectfully invite the Inquiry to consider the following steps designed to ensure a process for renovation of the Scheme:
11. First, the Inquiry should seek to ensure that government undertakes a full review of the Scheme and IBCA, with proper consultation at its core. The Inquiry may wish to suggest its own involvement in that process; or for that process to be judge-led.⁴ A true process of consultation with the infected and affected must take place, with appropriate involvement by lawyers who represented members of the community at the Inquiry. It should cover the issues raised in this note, and in the recent hearings, but also be open to new matters that will arise on consultation. That review must be open to amending the Regulations⁵ where problems have already been or are later identified. It should proceed in tandem with the implementation of the existing Scheme. Where changes are required, any adjustments to payments can be made through retrospective supplementary payments, causing no delay to ongoing implementation. There is no reason why such a review should delay IBCA's work — and every reason why it should enhance it.
12. Second, as the Minister has confirmed the overarching principle that any amendments to the Regulations governing the Scheme will be assessed against the risk of delay to compensation, the Inquiry should clarify the procedure by which the Scheme and its Regulations may be amended. This includes identifying the relevant powers, the steps required, and the likely timescales. It is important to establish what changes are possible,

⁴ As per Recommendation 14 of the Inquiry's Second Interim Report INQY0000453

⁵ The Infected Blood Compensation Scheme Regulations 2024; The Infected Blood Compensation Scheme Regulations 2025

and how quickly they can be made. In truth, there is no reason why substantial amendments cannot proceed quickly and in parallel with implementation of the existing Scheme. Delay must be considered, but it cannot be a shield against necessary reform.

Third, the Inquiry should scrutinise the independence of the IBCA and recommend both a clear definition of “independence” and a mechanism to ensure it is meaningfully upheld.

Part 2: Specific issues

How IBCA should operate in the future

13. The future operation of IBCA must be grounded in transparency, accountability, and sustained — effective — engagement with those it serves.⁶ The experience of infected and affected individuals and the lessons of past failures, demand a model of administration that is not only procedurally sound but also responsive, humane, and inclusive.
14. The Inquiry should recommend concrete steps to embed genuine consultation and collaboration within IBCA’s structure. This must include meaningful representation of infected and affected communities—not only in advisory roles but at all levels, including on the Board. Recognised Legal Representatives (‘RLRs’) should be actively involved to uphold legal safeguards and help rebuild trust. Standing expert committees, comprising legal and community representatives, should be established to guide key areas such as evidence collection and Scheme design, ensuring that the Scheme is informed by lived experience and legal expertise from the outset. IBCA must also retain the flexibility to draw on additional expertise—such as psychologists and trauma specialists—ensuring its approach remains informed, inclusive, and responsive.
15. Mental health safeguarding must be a core operational principle. Many claimants will be required to revisit traumatic experiences in order to engage with the Scheme. IBCA must have clear protocols in place to identify and support vulnerable individuals, including access to appropriate psychological support where needed. This is not ancillary to the

⁶ LDOW0000364

Scheme's function — it is central to its legitimacy. It must be available to all, irrespective of whether they are enrolled with a support scheme.⁷

16. Transparency must extend to IBCA's internal processes. The organisational structure and roles of individuals, the training of decision-makers, the criteria applied in assessments, and any changes to policy or interpretation must be clearly communicated to the community. Applicants must be able to understand how decisions are made and to expect consistency in how claims are treated. Without this, confidence in the Scheme will erode.
17. Clinical advice must be grounded in the standards that were in place at the time of infection or treatment. In order to ensure clinical advisors are aware of historical issues there should be training that includes, but is not limited to, the overuse of blood, top-ups and the use of blood transfusions for new mothers following childbirth. It would be unjust to assess historical events through the lens of present-day medical knowledge and practice. IBCA must ensure that its clinical advisors are instructed accordingly, and that this principle is applied consistently. In addition, it creates a very real risk that the IBCA will continue to repeat mistakes of the past and mirror decision-making by the existing Infected Blood Support Schemes ('IBSS') and Alliance House Organisations ('AHOs'). The IBSS and AHOs assess applications on a balance of probabilities, but often fail to consider the absence of medical evidence or what would have occurred in practice during the applicant's treatment period. If the IBCA adopts the same approach, individuals may be denied compensation despite the extensive findings of the Inquiry. This is not only a moral imperative for procedural reform, but also a logical necessity—otherwise, what was the point of the last seven years?
18. IBCA must also ensure that it has access to a sufficient number of clinical assessors with relevant expertise — including knowledge of blood transfusion and use of blood products during the relevant periods. At present, there appear to be only one or two such assessors. That is not adequate for the scale or complexity of the task.

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19. To ensure that those entitled to compensation are properly supported from the outset, the Inquiry should also recommend that access to legal representation by specialist lawyers is both funded and clearly signposted at the point any claim is registered and throughout the process. Early engagement with RLRs is essential—not only to safeguard claimants’ rights, but also to promote confidence in the Scheme’s fairness and accessibility from the very beginning.
20. IBCA must retain a degree of discretion to respond to exceptional or unforeseen circumstances. This flexibility is not adequately provided for by the proposed Severe Health Award, nor can it be if every possible scenario must be exhaustively defined in legislation.
21. Where changes are made to the underlying Regulations, IBCA should proactively identify and contact individuals who have already received compensation, to ensure that any additional sums due as a result of those changes are paid. This is a matter of fairness and administrative competence. Additionally, the IBCA should advise those who accept, or have accepted, compensation prior to further consultation on the Regulations, will receive any difference in compensation.⁸

Prioritisation

The proposal made by the Inquiry regarding prioritisation⁹

22. We note the proactive proposal made by the Inquiry on 12 May to prioritise claims-processing by ranking various factors across the categories of (a) people infected (b) people affected and (b) in respect of people deceased.
23. It has not been possible in the time available before this submission to take full instructions on the range of issues raised and so we confine ourselves to points of principle in this note, although in the next subsection we set out a sample of some responses that we have received.
24. At this stage, we are able to make the following limited observations:

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- a. In principle, clear prioritisation is necessary, the outlines of which might be agreed in the renewed consultative process with IBCA that we have proposed in Part 1,¹⁰ above.
 - b. IBCA should have the operational capacity to prioritise multiple strands of assessment simultaneously. In particular, it should be able to progress the testing and processing of the three key categories identified above, rather than sequentially. This will help to avoid unnecessary delay and ensure that the Scheme remains responsive to the needs of all applicants.
 - c. The Inquiry is urged to press IBCA to address, as a matter of priority, the position of individuals who are infected but not currently registered within the existing compensation framework. This includes those infected with HBV, individuals infected with Hepatitis C after 1 September 1991, Hepatitis C self-clearers, and those whose medical records have been lost or destroyed. These individuals must not be left behind.
25. In any event, the Inquiry should press government and IBCA to scale their operation as rapidly as possible, with all available resources; it is this factor above all others that will expedite the necessary compensation.

Reflections on prioritisation

26. In the time limited available since receiving the Inquiry's proposal, core participants have expressed a range of views on the proposed prioritisation framework.¹¹ While there is broad support for prioritising those who are terminally ill or in urgent need, there is some concern that the current approach may unintentionally marginalise others whose experiences of harm remain unresolved.
27. One participant, a 35-year-old beneficiary of their late mother's estate, described the lasting emotional and financial impact of losing a parent at a young age due to infected blood. Although an interim payment was made to the estate, they emphasised that it did

¹⁰ p. 2

¹¹ LDOW0000366

not represent justice or closure. They expressed concern that the proposed framework would place their claim at the back of the queue, simply because of their age and the fact that an interim payment had already been received. They urged the Inquiry to recognise that younger age should not be treated as a proxy for lesser harm, and that interim payments should not automatically deprioritise a claim where the underlying loss remains unacknowledged. For many in this position, the compensation process is the only route to redress — and further delay risks compounding the trauma of premature loss.

28. Other participants 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.
29. A further communication raised concerns about the financial implications of delay. A participant infected with chronic Hepatitis C, aged 58 and treated with Interferon, noted that monthly support payments made after 30 April 2025 should not be deducted from final compensation where delays are due to government processing timelines. They also argued that compensation calculated at 2024 levels should be uplifted to reflect inflation, and that interest should be applied to account for the time lost. Without such adjustments, those processed later in the Scheme — through no fault of their own — risk receiving less in real terms than those whose claims are resolved earlier.
30. Together, these reflections highlight the need for a prioritisation framework that is 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.

The unregistered infected

31. As above, the Inquiry is urged to address, as a matter of priority, the position of individuals who are infected but not currently registered within the existing compensation framework, including those defined at paragraph 24. These individuals must not be left behind.
32. IBCA should begin work immediately to determine how applications from this group will be assessed. There is no justification for further delay. The evidential requirements and eligibility criteria must be published in advance of the Scheme opening to this cohort. This includes clarity on the standard of proof, the types of evidence that will be accepted where medical records are unavailable, and the process by which such evidence will be evaluated. Without this transparency, individuals will be unable to prepare their applications or challenge any assumptions made behind closed doors. The longer it takes for guidance on alternative evidence to be published, the less likely individuals will be able to locate it. The principle must be that no one is excluded from compensation due to administrative inertia or evidential uncertainty that is not of their own making.
33. 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.¹²
34. Those in this group who meet the eligibility criteria should receive interim payments without delay. They should also have the opportunity to apply for ongoing monthly support, including Special Category Mechanism (SCM) payments where appropriate. They should therefore have the option to accept an offer under the Core Route or under the IBSS route.
35. To minimise delays in processing applications, IBCA should assess whether additional resources need to be allocated to NHS haematology and hepatology teams. These teams are likely to face a significant administrative burden in identifying and retrieving patient records — particularly for individuals previously unregistered and infected with HCV or

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HBV — and must be adequately supported to ensure timely and effective case handling.¹³

Compensation for those infected with Hepatitis C

36. The Inquiry is asked to consider the significant disparity in the level of compensation available to those infected with HIV compared to those infected with Hepatitis C. Individuals with chronic Hepatitis C — including those with cirrhosis — are to receive markedly lower awards, despite the long-term and often debilitating impact of the condition. This disparity is not only unjustified but undermines the principle of equal recognition for equal harm.
37. The process for applying also differs substantially. Those with HIV face a straightforward route, while those with Hepatitis C are subject to a significantly more complex procedure. This includes navigating multiple pathways and demonstrating eligibility through documentation that may no longer exist or never existed because certain scans/treatments were not yet invented. These inconsistencies should be addressed, and we suggest that comparative data — such as the tables prepared by the Contaminated Blood Campaign¹⁴ — be considered by the Inquiry as they amply illustrate the great complexity and evidential burdens facing claimants with Hepatitis C.
38. The treatment of those eligible for the SCM award should be revisited. The categories of awards and the severity bandings need to better reflect the impact of the infections. This should be determined through consultation. This should include consideration for individuals eligible for SCM under the IBSS, or who would be eligible if registered, to receive an automatic uplift under the Severe Health Condition Award via the Supplementary Route (SR) or be moved into the level 3 severity band under the Core Route. We understand that the Expert Group recommended such uplift,¹⁵ but this was not implemented to the SR (and no changes have been made to the Core Route). We ask the Inquiry to seek clarity on why this was not implemented. This change(s) would better reflect the impact of their condition. Those not claiming or registered under IBSS should

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¹⁵ CABO0000925, p.57.

still have the opportunity to claim an uplift or increased monthly payments if they meet the criteria.

39. The Inquiry should seek clarity on how fibrosis and cirrhosis are assessed. David Foley's Third Witness Statement confirms that placing an individual in the level 3 severity banding, does not require a diagnosis of cirrhosis and claims managers seek assistance or clarity from clinical assessors when determining severity, but it is clear that IBCA rely heavily on Fibroscans and kPa results to do so.¹⁶ The Inquiry must seek clarity on the position for individuals who have not had Fibroscans or those who first started experiencing liver function abnormality before Fibroscans were invented and/or before they were introduced on the NHS. It is our understanding that raised ALT's is not sufficient evidence for this purpose.
40. The criteria regarding assessment of fibrosis and cirrhosis should be drafted by medical and legal professionals which must be published and comprehensively applied. The process must be consistent, transparent, and based on clear published guidance that considers the practices of the time in the context of the infected blood scandal. This may be a matter which should be considered through the consultation process.
41. Finally, the deemed/assumed years regarding the progression of liver disease under the Core Route should be amended (see Appendix for worked example highlighting errors).

Issues with the Supplementary Route

42. The following issues arise in respect of the Supplementary Route.
43. The SR must be revised to ensure it properly reflects the range and severity of injuries experienced by those infected, particularly with Hepatitis C.
44. Individuals with fibrosis that do not meet the threshold for cirrhosis are currently excluded from Level 3 awards under the Core Route, despite clear evidence of serious injury. If the severity bandings set out in the Core Route are to remain as set out in the Regulations, these individuals should be eligible for an uplift in compensation under the

¹⁶ WITN7757011, §12-17, p.6-7.

SR via the Severe Health Condition Award. This should extend to an uplift in the Injury Award as well as Financial Loss/Care Awards for the relevant period.

45. The SR should also be widened to recognise other life-changing and debilitating physical and mental health conditions associated with Hepatitis C and its treatment. These are relatively rare conditions that nonetheless affect a significant number of individuals, each bearing a heavy personal burden. They include, but are not limited to, osteoarthritis, fibromyalgia, cognitive impairment (often described as “brain fog”), type 2 diabetes, and heightened sensitivity to cold. Many of these are documented in Annexes 2, 3, and 4 of the final submissions made by Leigh Day on behalf of their Core Participants,¹⁷ and should be explicitly included in the Scheme’s criteria.
46. All people currently on the SCM should be accepted as eligible for the Special Health Award. This will expedite assessment and improve fairness, particularly in light of recently published evidence suggesting the narrowing of SCM categories was driven by financial considerations.
47. Consideration should be given to uplifting compensation under the SR not only for Financial Loss and Care Awards but also for Injury, Loss of Autonomy and Social Impact Awards. In addition, individuals treated with Interferon and/or Ribavirin — whose side effects are well documented — should be eligible for a distinct award reflecting the harm caused by those treatments.¹⁸ If no distinct award is introduced under the SR, changes can be made under the Core Route to remove the date it is assumed effective treatment was introduced where an individual received Interferon and/or Ribavirin.
48. The evidential standards applied under the SR must also be reviewed. 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.¹⁹

¹⁷ SUBS0000059, p. 453-479

¹⁸ LDOW0000364

¹⁹ NTHT0000059; LDOW0000364

49. Eligibility should be based on diagnosis, not treatment history.
50. The enhanced Financial Loss Award is currently too narrow for individuals infected as children who were unable to begin or build a career. These individuals should not be penalised for circumstances beyond their control.
51. Finally, applicants who have accepted a lump sum under the Core Route or received IBSS payments should be permitted to revisit that decision if they are successful under the SR. They should be able to choose between continued payments and a lump sum, depending on their needs.

Compensation for the affected

52. A SR should be developed for affected individuals to reflect the impact of infection of a loved one on their employment and education.
53. These claims should be processed in parallel with those of the infected person or their estate, and 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.²⁰
54. Part of the consultation process should be to address concerns of the community in relation to awards and set tariffs for affected persons.

Adjusting for inflation

55. Inflation will erode the value of compensation for those claimants who endure yet more years of administrative delay or whose claims are prioritised last. The delay is in no way their fault. Compensation levels should be uplifted, or interest applied, to account for inflation. The government has offered no tenable justification for a flat-rate approach that disadvantages those whose claims are processed later in the Scheme.

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Endorsement of Milner's Law submission on the future of the Inquiry

56. We endorse the position set out in the submission of Milner's Law titled The Future of the Infected Blood Inquiry. The submission (not repeated here, for brevity only) rightly argues that the Inquiry's role is not yet complete and that continued oversight is essential to ensure timely and fair implementation of its recommendations.
57. The Chair's decision not to declare the Inquiry's Terms of Reference fulfilled in May 2024 has been vindicated. Significant uncertainty remains — particularly for unregistered and bereaved claimants — and the Inquiry's continued presence has already helped accelerate progress.
58. We support the proposal that the Chair should only conclude the Inquiry once the compensation scheme is operating effectively for all cohorts, with a review point in 2026 to assess progress.

Other outstanding issues requiring clarification and reform

59. These further issues arise.
60. A formal checking mechanism must be introduced to ensure applications are completed accurately. IBCA should introduce a transparent review process during the test and learn phase, to ensure that claims are checked for accuracy at both the declaration form stage and the offer letter stage. They should ensure that this information is published.²¹ Concerns raised by RLRs in their 2 April 2025 meeting with IBCA — including errors in dates and claim details — highlight the need for a robust quality assurance process, particularly during the test and learn phase. Applications that have been finalised to date should be routinely checked and individuals contacted regarding any errors and awarded any supplementary payment as standard. This is particularly a concern for applicants who have not instructed legal representatives.
61. Support scheme payments should continue for widows and widowers where the infected person dies after 31 March 2025 and the IBSS route has been chosen.

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62. The Inquiry should also seek clarity on the inheritance tax (IHT) implications of compensation awards — both for estates where the infected person dies after receiving compensation, and for those who died before 23 August 2024.
63. The calculations for Financial Loss Award under the Core Route where the continuation of IBSS payments is accepted should be amended (see Appendix for worked example highlighting errors).
64. To ensure transparency and identify any emerging disparities, data on compensation offers made and accepted—as well as claimant satisfaction with the process—should be systematically collected and published. This data must be disaggregated by mode of transmission, virus type, and geographical region to enable meaningful analysis and responsive policy adjustments.
65. The one-year review proposed by the Inquiry must be conducted transparently and include a clear mandate to implement substantive changes to the compensation framework. This should explicitly include the ability to amend the underpinning legislation where necessary to ensure the scheme remains fair, effective, and responsive to claimants' needs.²²
66. Data on claimant satisfaction with the compensation process should be systematically collected and reported. In addition, the number of claims relating to transfusion and blood product-related infections should be routinely captured. This information is essential for monitoring the scheme's effectiveness, identifying trends, and addressing any emerging disparities.²³
67. Finally, the appeal process must be clarified. At present, there is no detailed provision in the Regulations setting out how applicants can appeal decisions following a review by the IBCA. This must be addressed, via consultation, to ensure procedural fairness and access to redress, particularly for applicants who have not, and do not wish to, instruct legal representatives. Further, IBCA must include an appeals mechanism with sufficient discretion to be capable of reviewing individual circumstances where an award fails to

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deliver just compensation. This mechanism should be empowered to consider the specific circumstances of each applicant and provide redress where the application of the Scheme's rules results in an unjust outcome.²⁴

Conclusion

68. We extend our gratitude for the foresight of the Inquiry in convening the hearings on 7 and 8 May. It is imperative to recognise the moral responsibility of ensuring that the IBCA gets on track to rapidly become an effective and efficient disburser of compensation. True, ongoing, consultative participation of the community of the infected and affected in addressing the known problems with the Scheme, and during its ongoing operation is essential in that process.

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23 May 2025

²⁴ LDOW0000364

Appendix

This appendix contains detailed explanations of issues arising in respect of:

- (a) deemed / assumed years regarding progression of disease;
- (b) certain aspects of the financial loss calculations.

For both issues, we have proposed simple adjustments to the scheme to amend the flaws identified.

(a) Deemed / assumed years regarding progression of disease

Summary

Summary of Regulation 20(7) and Its Impact: Regulation 20(7) of the 2025 Regulations allows for “deemed years” to be applied when an applicant lacks sufficient evidence to establish the severity of their infection and its progression over time. These deemed years follow a presumed progression of liver disease: 4 years in level 4 (most severe), 6 years in level 3, remaining years in level 2. This retrospective application starts from the date of the compensation application and works backwards.

Practical Impact: This approach can significantly undercompensate individuals. We provide below the example of ‘John Smith’ for whom the provision results in a substantial shortfall.

Current Practice and Inconsistencies: The IBCA appears to sometimes bypass Regulation 20(7) by awarding compensation based on diagnosis year, but this method is inconsistently applied and still omits the level 3 banding entirely in some cases. This leads to unfair / unpredictable outcomes and contradicts the Expert Group’s guidance.

Proposed Amendment: To ensure fairness, it is proposed that the “Relevant Date” in Regulation 20(7) be changed from the date of application to the date of diagnosis of the qualifying condition. This would mean that 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.

Conclusion: This simple amendment would correct a significant flaw in the current scheme, ensuring that individuals are not penalised for lacking historical medical evidence — especially when such evidence was often unavailable due to systemic failings.

Detailed Explanation

Regulation 20(7) of the 2025 Regulations confirms that if an applicant has not provided sufficient evidence to establish the level of severity of their infection for certain / all years of

their infection period, deemed years will be applied from the date of the application backwards. The deemed years follow the presumed progression of liver disease as set out by the Expert Group that is, four years in the level 4 severity banding, six years in the level 3 severity banding and the relevant remaining years will be level 2 severity banding.

In practical terms this means that if an individual has insufficient evidence, as deemed by the IBCA, of a cirrhosis or decompensated cirrhosis diagnosis date, they may be compensated under these severity bandings for shorter periods of time than they actually experience(d). The effect of this is that individuals have and will continue to receive less compensation than they are due. This point was acknowledged by James Quinault during the Inquiry Hearing on the 8 May 2025.²⁵

We have prepared the following example to explain the effect of this provision and set out appropriate and simple changes that could be made to correct it.

John Smith (for the avoidance of doubt, not a real person), born in 1949, received a blood transfusion in 1978 during a heart operation. In 2006, following investigations for other health concerns, Mr Smith was diagnosed with hepatocellular carcinoma. Investigations regarding the underlying cause of the hepatocellular carcinoma found Mr Smith had Hepatitis C caused by the blood transfusion he had received in 1978. At the same time Mr Smith was diagnosed with decompensated cirrhosis. Mr Smith was asked to apply for compensation in March 2025, unfortunately Mr Smith is receiving palliative care and does not have long to live.

Mr Smith is placed in the level 4 decompensated cirrhosis/liver cancer severity banding however, there is no evidence when his liver first became cirrhotic.

If 20(7) Regulation is applied, Mr Smith's assumed progression will be as follows:

- 2022 – onwards as level 4 (4 years backwards from the date of the application (i.e. 2025));
- 2016 – 2021 as level 3 (6 years backwards from the 4 years in level 4 banding); and
- 1978 – 2015 as level 2.

This application of the 20(7) Regulation should not apply to Mr Smith because he has evidence of decompensated cirrhosis and hepatocellular carcinoma from 2006. If it was applied, Mr Smith would be awarded compensation under the level 2 severity banding for ten years after his diagnosis of hepatocellular carcinoma. This defies logic.

During our experience with the Scheme thus far, it is our understanding that claims managers will take a different approach to Regulation 20(7) that ensures higher levels of

²⁵ INQY1000284, p. 151-153

compensation, but that approach is still not logical and disregards the presumed progression periods set out by the Expert Group. We are also not clear if this approach is applied consistently.

The approach taken by some IBCA Claims managers means individuals are placed in the highest banding from the year they are diagnosed but for individuals in Mr Smith's position, they are not awarded compensation under the level 3 banding at all. It works as follows:

- 2006 onwards level 4; and
- 1978 to 2005 as level 2.

Mr Smith has not been placed in the level 3 banding during any period within his entire infection period as he has not been diagnosed with cirrhosis. In terms of evidence available to him, there are limited liver function tests in his medical history and until recently, Mr Smith has never had a Fibroscan. His severity progression is marked as chronic Hepatitis C to decompensated cirrhosis/hepatocellular carcinoma by the IBCA overnight.

Not only does this approach ignore the Expert Group's view it also does not take account of the evidence given throughout the Inquiry in relation to treatment, progression management and diagnosis; many individuals were not diagnosed with Hepatitis C until they had been diagnosed with liver cancer meaning there is no evidence of progression throughout their infection period.

In terms of the compensation payable under each of these approaches, there is a clear difference:

Head of Loss	Offer as is Level 2 from 1978 – 2005 Level 4 from 2006 (onwards)	Regulation 20(7) (working backwards from date of application) Level 2 from 1978 – 2015 Level 3 from 2016 - 2021 Level 4 from 2022 (onwards)
Injury	£180,000	£180,000
Social Impact	£50,000	£50,000
Autonomy	£50,000	£50,000
Care	£446,751.74	£446,751.74
Financial Loss	Basic FL Award: £12,500 Additional FL Award: Level 2: 1978 – 2005 at £11,863 Level 4:	Basic FL Award £12,500 Additional FL Award: Level 2: 1978 – 2014 at £11,863 2015 at £5,931.50 Level 3: 2016 – 2021 at £11,863

	2006 – 2014 at £29,657 2015 – 2037 at £14,828.50 Total: £940,132.50	Level 4: 2022 – 2037 at £14,828.50 Total: £753,296.50
Total	£1,679,384.24	£1,492,548.24

In this instance while Mr Smith has been awarded £186,836 more than would be awarded to him if 20(7) Regulation was applied however, the offered compensation is without any deemed progression of his liver disease meaning Mr Smith has not been compensated appropriately.

Because Regulation 20(7) is not applied by IBCA unless individuals are diagnosed with the severity change in the year in which they apply for compensation, it is redundant. The only exception is deceased claims where an individual is unlikely to have any evidence of disease progression except perhaps what is listed on a death certificate but that does not confirm year of diagnosis. In this instance the deemed years can be applied from the date of death backwards as is set out in Regulation 20(7). However, in instances where evidence can be provided, it should be as set out below.

We propose that for living individuals, a change can easily be made to amend the definition of 'Relevant Date' within this specific Regulation from the date of application to the date of diagnosis of condition that makes them eligible to be placed within the level 4, if not, level 3 severity banding. It will mean the deemed years presumption is applied from the date of diagnosis backwards. If this change was made, it would work as follows:

- 2003 onwards level 4 (4 years backwards from the date of diagnosis (i.e. 2006));
- 1998 to 2002 as level 3; and
- 1978 to 1997 as level 2.

In terms of the compensation payable should this change be made, there is a stark difference:

Head of Loss	Amendment to Regulation 20(7) (working backwards from date of diagnosis) Level 2 from 1978 – 1996 Level 3 from 1997 - 2002 Level 4 from 2003 (onwards)
Injury	£180,000
Social Impact	£50,000
Autonomy	£50,000
Care	£446,751.74

Financial Loss	Basic FL Award £12,500
	Additional FL Award:
	Level 2: 1978 – 1996 at £11,863
	Level 3: 1997 – 2002 at £23,726
	Level 4: 2003 – 2014 at £29,657 2015 – 2037 at £14,828.50
Total	£1,803,944.24

This approach entitles Mr Smith to £311,396 *more* in compensation than what would be payable if Regulation 20(7) was applied and £124,560 *more* in compensation than what Mr Smith would receive if awarded compensation using the approach IBCA appear to have taken to date because Regulation 20(7) is not fit for purpose. This represents a difference of over 20% and over 7% respectively.

This appears a very simple change that is not fully understood by the Cabinet Office. In further witness evidence,²⁶ James Quinault has confirmed that in the circumstances as set out above, the difference in awards is significant but small in the context of things, usually around 3.5% less compensation overall. This is not relevant, individuals should be compensated appropriately and in some cases it is not just 3.5% it can be much higher than that.

Mr Quinault goes on to suggest that the approach set out above will be unfair in circumstances where individuals can provide evidence that their disease progression is longer than the presumed four or six years, but this is not our clients' position. In circumstances where evidence cannot be provided of progression, the deemed years will be applied from the date of diagnosis backwards. In circumstances where progression can be evidenced, that evidence prevails and those dates are used. This is the same if the progression period is longer or shorter than the deemed position.

Overall, this is the fairer approach and ensures individuals are compensated appropriately.

To not take this step is to again ignore the arguments made by the Community (that were accepted by the Inquiry) – 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 where it was urgent and even then it was not always successful. To repeat the notion that individuals will have evidence, if not

²⁶ INQY1000284, p.154, I.6-7

they will not be compensated is ignorant to all that has been said, very loudly, for many decades and perpetuates the harms the Community has already endured.

(b) Financial Loss Calculations

Summary

Summary: The 2025 Regulations introduce a formula that deducts a percentage of an applicant's past financial losses from their total financial loss award. This approach contradicts earlier government assurances and results in under compensation. It has a particularly disproportionate effect on young people.

Case Example: The example of Mrs Samantha Jones (a fictional example) is provided below. If her Financial Loss Award were to be calculated in a similar manner to the approach taken in personal injury claims generally (as is applied under the Core Route), she would receive a greater award that more precisely reflects her losses.

Proposed Change: Remove the formula and calculate past and future financial loss based on losses up to the date of application, without deduction. This method is both precise and accurate, aligning with standard personal injury practices and restoring trust in the compensation process.

Detailed explanation

As set out in Gene Matthews' Witness Statement dated 2 April 2025, the 2025 Regulations contain a formula to calculate the past and future aspects of the applicant's financial loss. This formula deducts a percentage of an applicant's past losses from their entire financial loss award. This is in direct contradiction with the government's previous statements.

We have prepared the following example to explain the effect of this provision and set out appropriate, and simple, changes to correct it.

Mrs Samantha Jones (not a real person), born in 1964, received a blood transfusion in 1987 during the birth of her son. In 2014, following investigations for other health concerns, Mrs Jones was diagnosed with Hepatitis C caused by the blood transfusion she had received in 1987. Mrs Jones received treatment in 2015 and fortunately her liver remains healthy. She was diagnosed with rheumatoid arthritis in 2020. She now receives SCM payments from the IBSS because the rheumatoid arthritis was caused by the Interferon treatment. Mrs Jones was asked by the IBCA to apply for compensation in March 2025.

Mrs Jones has been offered the following compensation:

Head of Loss	Core Route	IBSS Route
Injury	£60,000	£60,000

Social Impact	£50,000	£50,000
Autonomy	£40,000	£40,000
Care	£54,600	Past Care Award: £24,862.50 (using the formula from the Regulations, the future Care Award is calculated at £21,450.00)
Financial Loss	Basic Financial Loss Award: £12,500 Additional Financial Loss Award: £492,303 This is broken down as follows: 1987 – 2016 at £11,863 = £355,890 2017 – 2029 at £5,931 = £77,103 2030 – 2049 at £2,965.50 = £59,310	Past Financial Loss Award: £298,898.25 (using the formula from the Regulations, future Financial Loss Award is calculated at £193,404.75)
Total	£709,403.00	£473,760.75 lump sum and the continuation of the support payments each month

If the past Financial Loss Award was calculated similar to the approach in personal injury claims generally (and how it is calculated under the Core Route), i.e. from the year of infection to the date of application, the sums would be £404,820.75. The calculations is as follows:

- 1987 to 2016 at £11,863 per annum = £355,890
- 2017 to 2024 + 0.25 (to include Jan – March 2025) at £5,931 per annum = £48,930.75

This is £105,922.50 *more* than what is awarded under the Scheme in respect of the past Financial Loss Award and is a significant sum to deduct.

We propose that the Inquiry recommends the formula is removed for the past and future financial loss award and is calculated on this basis moving forward. Not only is this calculation a quicker and simpler approach, it provides both accurate and precise compensation.

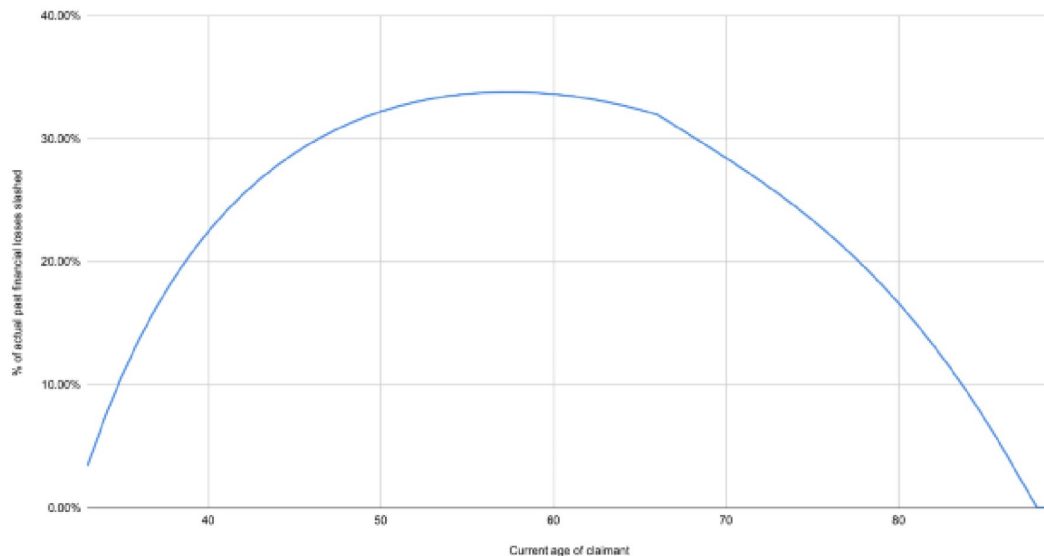
At the Inquiry hearings on 8 May 2025, James Quinault asserted that while this way of calculating the Financial Loss Award is possible and may look more precise, he does not think it would be more accurate.²⁷ This is not correct. Calculating the Financial Loss Award in this way is both precise and accurate as it awards individuals the exact sum they are entitled to receive under the Scheme for each year of their infection period.

²⁷ INQY1000284, p. 151-153

The formula in place does the opposite, it averages the Financial Loss Award for each year within the period of infection. This disregards the fact that the future Financial Loss Award is deducted following the year the applicant turns 66 years of age so is likely to be a lesser sum and appropriately so as the individual is no longer employed for the purposes of the Scheme and this would likely be the case 'but for' the underlying condition.

It also directly contradicts what the government confirmed would happen in relation to continuing the support payments and again perpetuates the lack of trust held by the community for the government.

As the Inquiry has heard, the formula disproportionately affects younger individuals as illustrated by the graph below, particularly those who are placed in the level 2 severity banding as they will likely wish to continue the support payments in addition to a smaller lump sum.



In his Second Witness Statement,²⁸ James Quinault fails to engage on the specific points regarding age discrimination save for that the government does not believe this is the case. He suggests that because the past Care Award is also deducted using a similar formula and averaged in the same way as the past Financial Loss Award, this is a fair approach in that the need for care is likely to be in the future period of an individual's infection period but part of this award is also paid in the past period, despite the fact individual's may not need it. This is not an appropriate assessment considering each award is calculated separately. Just because the past Care Award is calculated in this way does not mean the past Financial Loss Award should be too. The change can be made without affecting the past and future Care Award at all.

²⁸ WITN7755003, §180-192

