

INFECTED BLOOD INQUIRY

SUBMISSIONS ON COMPENSATION AND IBCA

ON BEHALF OF THE HAEMOPHILIA SOCIETY

1. These submissions are made by the Haemophilia Society ("the Society") on its own behalf and on behalf of its members, to include those designated with Core Participant status in the Infected Blood Inquiry ("the Inquiry") and represented by Eversheds Sutherland (International) LLP. This submission relates to the additional hearings on 7 and 8 May 2025. Those hearings were convened by Sir Brian in response to the outpouring of community distress caused by the Government's response to his compensation recommendations.
2. These submissions make some general observations and provide specific information. They end with a list of "asks" some general and some specific. The deadline for these submissions is 4pm on 23 May. On 20 and 21 May, the Cabinet Office disclosed further statements and documents. The Society is grateful to Sir Brian for allowing Core Participants to file additional submissions in response to that late disclosure.

2.1 Speed Without Justice

- 2.2 The Paymaster General, Mr Thomas-Symonds, has made a decision to prioritise speed of pay out over all else. He wants compensation done quickly rather than right. That is illustrated by this exchange between Ms Richards KC and the Mr Thomas-Symonds [transcript May 7 pages 182 to 183]:

Q. Would you accept that had the Government engaged better with the community and heard what was being said over the last weeks and months, you would have started reconsidering these matters months ago?

A. Look, I don't come here to offer a counsel of perfection, of course, and I think there's always an argument that if you take in particular steps they might have had different results. On the other hand, particular steps might have had more negative results. But I don't come here to offer a counsel of perfection. I come here in the spirit of construction. Whereas I think everybody has the same objective here of wanting to make the compensation payments more quickly.

Q. You've talked about a very important yardstick for you being avoiding further delay. In circumstances where it could be said it's the Government's failure to listen, hear, engage with the community -- and I'm including the previous Government very much in this -- that's caused delay, is it fair that that effectively should be visited now upon the community by not embarking upon a fresh look at some of their concerns?

A. Well, I don't -- it isn't -- it's where we are as of today, and it is simply the test that what I think everybody collectively wants to do is to ensure people get their money as soon as possible and to do something, now that's the test I set out earlier that would cause undue delay.

- 2.3 The Society makes the following points:
- 2.3.1 It is difficult to imagine what response to community engagement the Minister could have taken that would have resulted in as many negative results as the steps he actually took which appear to have been:
- 2.3.1.1 To go to community meetings with a closed mind so that he was unwilling or unable to hear and understand the information the community was giving him that, if heard, would have caused him to conclude that there were problems that needed fixing, what those problems were and how they could be solved;
- 2.3.1.2 Going away from these meetings and doing nothing;
- 2.3.1.3 Come to give evidence on 7 May not armed with proposed solutions but only with promises to go away and do the thinking that he could and should have done well before 7 May.
- 2.4 It is simply not the case that everybody has “*the same objective here of wanting to make the compensation payments more quickly*”. Of course victims would rather be paid sooner than later and whilst they are alive. But not at any price. Some – particularly those infected with Hepatitis C only who benefitted from the Special Category Mechanism (or its equivalent) and were told by Government they would transfer onto the Scheme’s supplementary route automatically – would prefer to suffer delay if that is what it takes to get just compensation. In short, the community’s objective is just compensation payments more quickly and just compensation payments more quickly for every victim of the scandal not a selection of them. The community is not interested in speed without justice: the evidence of the panel made that clear.
- 2.5 As The Society hopes the next section of these Submissions illustrates, it is vitally important that Government gets the Scheme right second time around. There is a greater chance of that happening if the Inquiry receives final submissions from Core Participants following receipt of:
- 2.5.1 Any further witness statements from the Minister, Mr Foley and Mr Tomas-Symonds on the list of matters they promised to reconsider;
- 2.5.2 Disclosure of documents;
- 2.5.3 Any proposals for improvements or modifications to the Scheme proposed by Government.
3. **AVOIDABLE DAMAGE ON AVOIDABLE DAMAGE – DOING BETTER IN THE FUTURE**
- 3.1 Too many times, the infected and affected have, quite literally, had Government heap upon them insult after injury. Every time there is a new Government, they hope for a different and better approach and every time, they watch in disbelief as the new Government repeats the mistakes and cruelties of its predecessors.

- 3.2 Even by the standards of the State failures and cover-up exposed in Sir Brian's final report, the rapidity with which Government transformed the relief caused by publication of Sir Brian's May 2024 into anguish and desperation has been exceptionally cruel.
- 3.3 Sir Keir Starmer's Cabinet Office could have undone some of the damage. It could have acknowledged that the Scheme should have been independent of Government. It could have agreed that not having a haemophilia specialist who treated people with haemophilia in the AIDS years on the secret Expert Group panel was a mistake. It could have looked after the bereaved instead of causing them financial fear in their grief.
- 3.4 As the servants of the people caused avoidable physical and mental trauma by the State, it could have listened and learned from the community it is supposed to serve with an open mind affording them dignity, respect and compassion.
- 3.5 Having inherited a problematic compensation framework, it could have been brave, bold and solution focussed. In a radical break from the past, having seen that mistakes had been made it could have gone to the real experts – the infected and affected and their lawyers and advocacy groups - and asked for help. It would have found an abundance of ideas for how to fill the Scheme's eligibility gaps and make good its compensation deficiencies. It could have heard the community's need for justice, not just speed.
- 3.6 This exchange between Counsel to Inquiry and Mr Quinault is instructive [Transcript 8 May pages 176-178]

Q. Does the Cabinet Office ever involve groups, people, victims in that policy development process or is it always working out a proposal and then consulting, I have in mind here the duty of candour, in particular what's happened with that?

A. So yes, it does. It's trying to do so in the case of the Duty of Candour Bill. And I think I can say, though I wasn't the decision-maker, that if -- I think if people had known that it would play out like this and that things would happen as they had, that they would have wanted to involve people at an earlier stage, even if at that stage that could only have been about broad principles rather than, you know, presenting sort of detail that people could grapple with. I think that would have been better and I think would have helped us avoid the situation that we are now in.

Again, I would say that I think if the Government had done that in, let's say, the autumn of 2023, I think there would have been a very understandable reaction of: well, why are you consulting us about sort of basic principles again? This surely being sufficiently established by the Inquiry and before that by Sir Robert Francis' compensation study. You know, what we want to hear now is kind of brass tacks, what is the Government actually proposing, and what would a scheme mean? And, certainly, when John Glen talked to community groups in May, they were kind of strongly saying to him, you know, enough time was wasted. You need to get on. You need to get on with it now and tell us what you mean.

So I think that would have been better, and if one had known how this has played out, that would have been a much, much better thing to do, but I speculate that it would also have had that sort of reaction.

3.7 The Society suggests that if, in the autumn of 2023, a listening Government intent on getting it right first time had engaged with the community, the proposals, as to the basic principles, would have avoided:

3.7.1 The setting up of a compensating body that was a creature of Government and not independent;

3.7.2 Obtaining medical advice from a secret panel of experts;

3.7.3 Receiving legal advice from a firm of solicitors with no prior knowledge of the infected blood scandal and exclusion of lawyers representing victims;

3.7.4 Setting compensation levels by Government and a toothless compensating body with no discretion to deviate from them;

and the impacts associated with each of the above.

3.8 The Society makes this request of Sir Brian:

A recommendation that when creating a compensation body and/or Scheme – Government seeks the views of those being compensated throughout the process and there are prescribed intervals at which an update has to be provided.

4. **DOING BETTER NOW: IMPROVING THE SCHEME AND AVOIDING CIVIL CLAIMS**

4.1 Mr Thomas-Symonds said this in answer to a question about what Ms Richards KC described as the in part “*frankly incomprehensible*” regulations [Transcript May 7 2025 page 171 lines 20-24]:

“clearly the purpose of having a broad-based tariff scheme to which victims can go means that you do not have the thousands of civil claims before our courts. That's what the idea is behind having a broad-based tariff scheme.”

He went on to say [page 172 lines 3-11]:

“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. And that's not a comment, I hasten to add, on the lawyers that are working very hard here. It really isn't. It's just a general point about learning from previous compensation schemes.”

4.2 The Society makes the following points:

4.2.1 Sir Brian had already done the learning for the Minister. Had Sir Brian's recommendations been implemented, the compensating body would have been informed by a legal panel comprising lawyers who had represented victims throughout the Inquiry. *The Government had already paid them and their experience thus came at no additional expense.*

- 4.2.2 It was, and remains, possible to put in place a tariff based scheme that incorporates an element of discretion by providing compensation bands rather than the set in stone, one size fits all, predetermined figures. Had that been done – as The Society hopes it will – IBCA would already be making payments tailored to individual claimants’ circumstances. The spectre of “*thousands of civil claims before our courts*” would have been laid to rest at proportionate cost.
- 4.2.3 Had Government created a compensating body in the way Sir Brian suggested it did, and had it adopted Sir Robert’s compensation framework, is it unlikely that there would have been any significant recourse to litigation. The decision not to implement various of the compensation recommendations made by Sir Robert and Sir Brian has given rise to a Scheme with a number of gaps and deficiencies. It is entirely foreseeable (and it may be predicted) that unless the gaps are filled so that all of those avoidably infected by contaminated blood and blood products are compensated to the extent that none is worse off than they would be on assessment of damages following proof of liability, there will be litigation.
- 4.2.4 The Inquiry will be aware that the Group Litigation Order made in October 2017 (*Jason Evans and Others v Secretary of State for Health* [2017] EWHC 3572 (QB)) has been stayed until 25 October 2025 pending awards being made under the Scheme (see *Webster & Others v Treloars Trust* [2025] EWHC 516 (KB) para 14)¹. The reason for the stay was:

“Clearly, there is no point in the litigation if the claimants in the litigation are going to get everything which they seek from their misfortune from the statutory scheme.”

- 4.3 The Judge in *Webster* decided (para 44) that those claims should not proceed “*until the potential claimants have made claims in accordance with the Scheme.*” Therefore, Government has an opportunity now, before claims are made to and determined by IBCA, to eliminate the gaps and make good the deficiencies in the statutory Scheme. If that is done, not only will there be no victim left uncompensated or undercompensated but also, tax payers’ money will be spent on those injured by the State not their lawyers.
- 4.4 The Judge in *Webster* said this (para 44): “*I regard the Scheme as a form of alternative dispute resolution.*” In his updated IBCA Recommendations dated 18 October 2024² under the heading “*What can be done to mitigate the concerns raised?*”, Sir Robert made this observation:

¹ In *Webster*, the judge observed (para 42) that he had not been provided with any comparative calculations in relation to the likelihood of a short fall in damages between the Scheme and litigation. The Society has not undertaken that comparative exercise but it has provided to Counsel to the Inquiry some comparative calculations illustrating short fall in damages between different victims in similar but not identical positions under the Scheme.

² <https://www.gov.uk/government/publications/recommendations-to-the-government-from-sir-robert-francis-kc/infected-blood-compensation-authority-recommendations-of-sir-robert-francis-kc-to-the-government-on-the-proposals-for-a-compensation-scheme-html>

“Candidly, no compensation scheme is going to be completely successful in matching the injuries of all individual victims, while ensuring a relatively simple and expeditious process. A struggle for perfection must not be allowed to be the enemy of overall justice.”

- 4.5 That was echoed by Mr Quinault. He agreed with Ms Richards KC that there are groups of victims for whom the Scheme does not provide the compensation that would be awarded following proof of liability, for example in relation to financial losses caused by loss of education, loss of earnings and loss of career opportunity [Transcript 8 May 2025 pages 165 to 167]. There are also individuals suffering specific injuries caused by avoidable infections which injuries are not compensated by the Scheme.
- 4.6 If, on reconsideration of the unfairnesses built into the Scheme, the Government does not make ineligible victims eligible or address inadequacies in compensation (whether because of the limits of what secondary legislation can achieve or for another reason) then The Society asks Sir Brian to recommend that Government works with Sir Robert and lawyers for infected and affected Core Participants to formulate an ADR protocol which victims can access and to which IBCA can divert relevant applications.
- 4.7 The Society asks Sir Brian to recommend that the Government appoints one or more lawyers with knowledge of the issues gained through working on the Inquiry and gives them a remit to enter into ADR with these groups with the aim of achieving just compensation for those victims whom the statutory Scheme is not a suitable compensation vehicle.
- 4.8 The Society asks Sir Brian to recommend that victims who have engaged in ADR unsuccessfully should receive non-means tested, non-merits tested Legal Aid.

5. **CORRECTING SCHEME DEFICIENCIES**

- 5.1 In the Infected Blood Inquiry’s Second Interim Report, dated 5 April 2023, at pages 18 to 24, Sir Brian set out his intentions in relation to the compensating body. Unfortunately, the recommendations have not been implemented as intended. In order to correct the scheme deficiencies, the Society makes the following suggestions.

5.1.1 **A Legal Panel**

- 5.1.2 One reason why the Inquiry recommended that the Scheme be created in consultation with the lawyers who have represented the infected and affected and the communities involved (people with haemophilia and people receiving transfusions of contaminated blood) was so that error would be avoided. It was entirely predictable – and likely predicted by Sir Brian – that if the Cabinet Office devised a Scheme with lawyers who knew nothing about the people the Scheme was to serve, it would create a Scheme that was not fit for purpose. So it has proved.

5.1.3 The Society suggests that:

- 5.1.3.1 IBCA immediately sets up a legal panel, Chaired by Sir Robert Francis, comprising lawyers for infected and affected Core Participants which should start work immediately;

- 5.1.3.2 The legal panel should devise and implement a process for assessing compensation where an award within a bracket is made and an appeal process;
- 5.1.3.3 The legal panel should identify groups of being avoidably infected or affected who receive no compensation under the current Scheme;
- 5.1.3.4 The legal panel should devise a tariff and/or tariff brackets for those groups;
- 5.1.3.5 The legal panel should devise compensation brackets along the lines of those in the Judicial College Guidelines for the assessment of General Damages where it identifies that the tariff figures fail to take into account fully or at all special circumstances including, but not limited to:
 - (a) painful and disabling side effects of Interferon type treatments,
 - (b) development of inhibitors caused by avoidable infection(s) and/or their treatment(s),
 - (c) the effects of being infected as a child.
- 5.1.3.6 The legal panel should make recommendations for lump sum only compensation options for claimants who want freedom from IBCA including:
 - (a) what multipliers should be used;
 - (b) whether and how multiplicands should be staged to accommodate the risk of deterioration or alternatively whether claimants should be required to return to IBCA when their condition deteriorates and what deterioration should trigger a return; and
 - (c) a mechanism for assigning a present value to the support payments and allowing individuals to take the adjusted route but then convert the ongoing payments to a lump sum.
- 5.1.4 The legal panel's recommendations should be communicated to Government within a set period (perhaps 3 months), and Government should make a written decision on whether it accepts those recommendations together with its proposals for implementation, also within a set period.
- 5.1.5 The legal panel's recommendations and reasons for them and Government's response and reasons for its response should be capable of being recorded and available for scrutiny so that there is transparency of decision making.

- 5.1.6 IBCA should alert, in writing, infected and affected community groups and all those on its registers signing up for alerts to its recommendations and the Government's response to them.
- 5.1.7 It is recognised that the work of the legal panel as detailed above, should necessitate a clinical panel and a community panel, or at the very least medical advisors.

6. **GOVERNMENT PROGRESS ON RECOMMENDATIONS**

6.1 Recommendation 2 – A memorial

- 6.1.1 Sir Brian recommended in his report of 20 May 2024, that there should be a suitable national memorial with the infected and affected forming part of the steering committee established to fulfil this recommendation. The Society understands that the committee is only just being set up. The indications received by the Society to date suggest that the Cabinet Office is considering not implementing Sir Brian's recommendation that the committee be chaired by the community.
- 6.1.2 It has taken a year to simply set up this committee. The first year of meetings have been completely missed. And the only reason the community was brought back together was due to Sir Brian reconvening the inquiry, along with the Society's annual service of remembrance that took place in October 2024. The service of remembrance in October 2024 was the best attended in years, which indicates its importance to the community. In the grand scheme of things, this was not a complicated recommendation and there is no good reason not to have implemented it.

6.2 Recommendation 9 – Protecting the safety of haemophilia care

- 6.2.1 The funding for Recommendation 9 needs to be made available immediately to NHS England based on the needs of the recent peer review of haemophilia centres to ensure that the proper level of treatment and care for people with bleeding disorders can be provided as a matter of urgency. Funding needs to be provided to cover the costs of moving to recombinant products for all bleeding disorders where they are available, filling gaps in resources at haemophilia centres and setting up networks this should not have to be found from existing NHS resources.
- 6.2.2 Extensive work was carried out by the working group for recommendation 9 and proposals put forward to fill the large resource gaps at many haemophilia centres – as yet, nothing has been forthcoming. The working group meetings have been postponed as a response is still awaited from government who have passed this onto the DHSC. The centres are now under increasing pressure from a resource perspective. They are running clinics and caring for people with bleeding disorders, but a considerable amount of time is also spent collating and searching for notes and information to provide evidence to IBCA. The Society has received information from a specialist haemophilia nurse at the Royal Free detailing concerns around inconsistency in approach in requests for evidence from

Case Managers at IBCA and the length of time it takes to gather the relevant evidence. The individual stated:

“They need to understand that claimants have moved around. At least from children to adults. Notes don’t follow patients and referral letters may have limited details. Depending on where each hospital is up to with its switch to electronic records the old notes we need to source may be in different systems and not in any order which is why it takes so long to find the relevant piece. E.g. yesterday I needed to find information on a 65 year old man. His old notes were scanned when we moved to electronic records. There are over 4000 pages in no obvious order. I eventually found pages from 1995. It took 3 hours. Then I needed to go into current records for up to date hepatology report. 4 hours in total. Then print and scan what I’ve found. Plus time to ring him to let him know what I’m sharing.

I have 5 open cases. I have 6 hours paid per week. Most Centres have nothing extra to do this and are already overloaded with their clinical work. Not all of the clinicians who are contacted will have my background and may not understand the context of the questions. Many of the most experienced clinicians in Haemophilia are retired.

I’d love to help them if they let me. We are all on the same side”.

- 6.2.3 IBCA should work with NHS clinicians to find a way to efficiently gather the information they need from Haemophilia Centres. Perhaps having a named individual at the Centre as their liaison so they have a working knowledge of the information as a point of contact.

6.3 Recommendation 10 – Giving patients a voice

- 6.3.1 Recommendation 10(a)(ii) specifically referred to the funding for patient advocacy. As detailed during the hearings on 7 and 8 May 2025, the Society received its first ‘offer’ of £500,000 the week before the hearings, to be divided between the three charities. It is accepted that the funding should not be sourced from the funds earmarked for compensation or improving haemophilia care, but as set out in paragraph 21 of the fifth witness statement of Kate Burt, *“financially, the Society has received no support whatsoever... We are operating in a very difficult financial landscape, with ever decreasing funding sources. To ensure we are still here to support the next generation of people with a bleeding disorder as well as meet the demands of our members today, we urgently need the assistance of government funding”*.
- 6.3.2 On 14 May 2025, Nick Thomas-Symonds announced that recommendation 10 was in hand and that they were engaging with the charities. It was implied that this had been dealt with, but this is not the case. The three charities named in recommendation 10 have been asked to bid for a share of £500,000 (for one year) between them. The charities have separately been told that there is no current budget for additional funding in future years.

- 6.3.3 Multi year funding is what is needed and what was anticipated by Sir Brian's recommendation. The funding should be agreed with each charity individually and each should be treated separately without being forced to negotiate as a group or pitch against each other. The Inquiry heard evidence of how the community was at times fragmented, but this is not currently the case. The Society is concerned that making the charities pitch against each other will also have a detrimental effect on their relationships.

7. **LIST OF ASKS**

- 7.1 As stated above, the Society sets out below its areas of consideration for the Inquiry. The Society accepts that some of these will be easier to implement than others, but all should be fully considered.

7.2 Clarity About Time Periods

- 7.2.1 The Government has set out the compensation time periods for each virus for which IBCA provides compensation, setting out the event with which the time period begins and ends. However, the Society disagrees with their conclusions. The Society submits that IBCA should be given the discretion to reconsider the dates, subject to the receipt of sufficient evidence.

7.3 Disclosure - Transparency and Understanding

- 7.3.1 The Government should identify all documents considered when determining the time periods and disclose the documents relied upon and produced during its decision making process
- 7.3.2 If Government rejects any of IBCA's recommendations, or the recommendations of Sir Brian following the May 2025 hearings, it should identify all documents considered when considering those recommendations and disclose the documents relied upon and produced during its decision to adopt or reject process.

7.4 Impact Assessments

- 7.4.1 If Government rejects any of IBCA's recommendations, or the recommendations of Sir Brian following the May 2025 hearings, the Government should carry out impact assessments, of the type carried out in 2016 in relation to the Hepatitis C infected.
- 7.4.2 Those impact assessments should estimate the number of people impacted negatively and should adopt the widest possible "liability windows" (to use the language of the unknown individuals providing IBCA with legal advice).
- 7.4.3 The Impact Assessments should be undertaken in collaboration with the Haemophilia Societies, Hepatitis C Trust and other major charities supporting the infected blood infected and affected.

7.5 Notification of Deaths

- 7.5.1 As far as the Society is aware, IBCA is unable to track deaths and it is anticipated that the data provided by the IBSS and IBIEPS schemes will be limited. Estates will contact the schemes to inform them of the death, but the Society is unaware of the process for sharing this information with IBCA. It is essential that this information is shared with IBCA along with details of any next of kin.

7.6 Registration Schemes

- 7.6.1 IBCA should immediately open registration lists for:
- 7.6.1.1 The affected;
 - 7.6.1.2 Bereaved partners;
 - 7.6.1.3 Those infected who are not currently registered on a scheme. IBCA should set up a system to assess those who have applied to the IBSS schemes and for whatever reason have been declined whether at stage one or SCM or 2. There needs to be an open and transparent process with clear published guidance agreed between IBCA clinical assessors and current treating clinicians; and
 - 7.6.1.4 Loved ones lost before the schemes were in operation.

7.7 EIBSS Payments for Partners Bereaved on and after 1 April 2025

- 7.7.1 IBSS payments should be made to all partners bereaved on or after 1 April 2025, those payments backdated to date of death.

7.8 Legal Aid

- 7.8.1 Non means and non-merits tested Legal Aid should be made available for victims ineligible for IBCA compensation and victims undercompensated by IBCA.

7.9 Date of Infection and Diagnosis

- 7.9.1 The Government's Scheme requires that applicants prove their date of diagnosis for those with Hepatitis C. That requirement is unnecessary and it causes avoidable detriment because it prevents those who cannot prove their date of diagnosis from accessing IBCA compensation.
- 7.9.2 The Society proposes that the Regulations are amended so that the requirement is for proof of date(s), or the date range, of exposure to blood borne viruses, not infection with blood borne viruses (to align with the

UKHCDO recommendations). Many people lived and suffered with these infections for many years before undergoing any tests to confirm the position. These individuals should be compensated for that suffering.

7.10 The 2016 Effective Treatment 50% Reduction

- 7.10.1 The Society asks Sir Brian to recommend that the blanket application of the 50% reduction in annual financial loss award to those infected with Hepatitis C from the implementation of effective treatment for Hepatitis C is removed.

7.11 Under Compensated

- 7.11.1 The Society believes that the following cohorts of individuals will be under compensated on the current tariffs:

7.11.1.1 Those infected with Hepatitis C who were treated with and experienced side effects of Interferon/Ribavirin etc;

7.11.1.2 The mono-Hepatitis C infected;

7.11.1.3 The Hepatitis C infected adversely affected by the 2016 effective treatment date decision;

7.11.1.4 Those bereaved on and after 1 April 2025; and

7.11.1.5 Those who died young.

- 7.11.2 We provide further information in respect of each of these categories below.

7.12 Treatment for Hepatitis

- 7.12.1 The side effects and devastating long term impact of interferon has not been captured within the compensation framework. The pain and suffering these individuals endured is not captured within the core awards and should be recognised as a category in itself. As things currently stand, those who suffered side effects of Interferon are compensated via the core award. They will get the same amount as a Hepatitis C infected person who didn't receive such treatments, or who did but suffered no side effects. The Society submits that this is unfair.

- 7.12.2 Many people had to undergo two or three rounds of treatment that lasted either 24 or 48 weeks depending on the strain of Hepatitis they had. The Inquiry expert report on Hepatitis stated that "the side effects were so bad this was a barrier to people accepting treatment". The devastating effects on their lives when undergoing the treatment were sometimes far worse than the impact of living with Hepatitis C in the long term. The Inquiry heard significant evidence in respect of the impact of the interferon treatment on individuals, to include:

7.12.2.1 Paul Sartain, pages 11 to 16 references two rounds of treatment, page 19 and pages 100 to 107³;

7.12.2.2 WITN0010, pages 9 to 12 and 13 to 14⁴;

7.12.2.3 Luke O'Shea-Pillips, pages 6 to 9⁵.

7.12.3 The Society suggests, that in order to adequately compensate this group fairly, there should be an additional lump sum award made. It has been suggested that that this should be c.£100,000 in addition to the financial loss award being on a par with the cirrhosis payment.

7.13 The mono-Hepatitis C infected

7.13.1 It is submitted that the core award does not adequately, or at all, reflect matters such as:

7.13.1.1 The psychological impact of diagnosis with HCV and living with the virus including anxiety, depression and suicidal ideation;

7.13.1.2 Fatigue;

7.13.1.3 Brain fog.

7.13.2 Further, based on the current system, these applicants do not meet the criteria for a serious health condition which is the gateway to a supplementary award for care or financial loss. To put it another way, they are more impacted than the core award allows but insufficiently impacted to get access to the supplementary awards as the criteria for those are so tightly drawn that the vast majority of people exceptionally impacted are excluded. The cohort of Hepatitis C only infected fall between two stools. The Society estimates that about 30% of its mono-infected membership is under compensated in this way.

7.14 Special Category Mechanism

7.14.1 The Skipton and Caxton Trusts were originally set up to support those living with Hepatitis C and were transferred to the devolved nations' IBSS organisations in 2017. They inherited a two stage system: Stage One for those who could demonstrate they had lived with Chronic Hepatitis C; and Stage 2 which provided additional support for those with additional impacts on their livers and some other specific conditions.

³<https://www.infectedbloodinquiry.org.uk/sites/default/files/Tranche%20E%20Statements%20copy/Tranche%20E%20Statements%20copy/WITN1013001%20-%20Written%20Statement%20of%20Paul%20Sartain%20-%2010%20Sep%202020.pdf>

⁴<https://www.infectedbloodinquiry.org.uk/sites/default/files/2a-4/2a-4/WITN0010001%20Written%20statement%20of%20%5BW0010%5D.pdf>

⁵<https://www.infectedbloodinquiry.org.uk/sites/default/files/documents/WITN1696001%20-%20Witness%20Statement%20of%20Luke%20O%27Shea%20Phillips.pdf>

- 7.14.2 A consultation process into “*Infected blood reform of financial and other support*” sponsored by the Department of Health took place from 2015-April 2016. In July 2016, a report set out the findings of this consultation. The report acknowledged the additional suffering for those infected with Hepatitis C and stated that reforms were needed⁶. Page 16 sets out the reasons for looking at a new category of support and page 17 lists the proposed reforms.
- 7.14.3 In 2017, it was recognised that there was a group of people living with chronic Hepatitis C which was suffering long term health problems that had an impact that went beyond Stage 1 and which were different to the impacts defined in Stage 2. For this group was devised what came to be known in England as the Special Category Mechanism (“SCM”) (EIBSS), Severely Affected for SIBSS, Enhanced Payments for NIBSS and Hepatitis Stage 1 Plus for WIBSS. Attached at Appendix [xxx] is a copy of the Northern Ireland response to the consultation on Enhanced Payments. This evidences the consultation and outcome of accepting the additional impact.
- 7.14.4 This clearly demonstrates that the impact of living with chronic Hepatitis C for some people was recognised as more severe than for others. The evidence in support of each SCM and equivalent additional payments application was submitted by treating healthcare professionals who for many had been caring for the individual applicant for many years and who would have borne witness to the impact of Hepatitis C on that individual.
- 7.14.5 The submitted evidence was assessed by medical professionals who were employed as medical experts within the IBSS schemes. Only then would the individual be accepted onto the scheme or equivalent category.
- 7.14.6 On 23 August 2024, the government published a policy paper; *Infected Blood Compensation Scheme Summary: August 2024*⁷. Annex C of this document (Health impacts eligible for Supplementary Route Awards) provides an outline of the health impacts that may qualify a person for higher financial award. Some of these criteria have been incorporated into the Supplementary Infected Blood Compensation Scheme Regulations 2025⁸.
- 7.14.7 In the last section of the table at Annex C, “Other associated disorders resulting in long term severe disability related to Hep C and B”, sets out a list of criteria by which people had been accepted onto the SCM or equivalent category in the devolved nations. These have not been accepted on the new Supplementary Route.
- 7.14.8 Despite all of the people having to provide medical evidence to be accepted onto the SCM and it being subsequently reviewed by clinical assessors those individuals have now been excluded from the newly devised supplementary route. The result is a group of individuals whose specific pain and suffering was formally particularised and described, evidenced by

⁶ [Infected blood: Government Response to Consultation on Reform of Financial and Other Support](#)

⁷ [\[Withdrawn\] Infected Blood Compensation Scheme Summary: August 2024 - GOV.UK](#)

⁸ [The Infected Blood Compensation Scheme Regulations 2025](#)

healthcare professional witnesses, objectively assessed by an overseeing body and accepted as worthy of additional compensation. In 2024, a promise was made to that group that they would transfer onto the supplementary route without having to evidence their eligibility again. Now, following advice from the secret expert panel, Government has reneged on its promise and told this group that its additional suffering and negative health and life experiences are no longer recognised.

7.14.9 The Society asks that all of those people who have already been assessed under the SCM or equivalent, be uplifted to the next level of financial payment (cirrhosis level), in line with other supplementary health conditions, starting from the year at which this level of impact began based on the evidence provided and accepted by the IBSS schemes.

7.14.10 The inequality continues where those who choose to continue with the support payments, who receive SCM, those payments will continue. However, those who would prefer to receive a lump sum will be at a disadvantage as the additional financial loss award will only be calculated at the chronic level. A worked example of the potential compensation payable is provided at Appendix [x].

7.15 The Hepatitis C infected adversely affected by the 2016 effective treatment date decision

7.15.1 The Scheme submits that the effective date of treatment for those born after 1961 and infected with HCV is 2016. The Scheme assumes that in and from 2016, the HCV infected get better and go back to work and halves the annual amount of compensation for financial loss after 2016.

7.15.2 Most of the Society members who are applicants to the Scheme were treated before 2016 and therefore did not have the post 2016 treatment.

7.15.3 As a result: not only are this cohort receiving no compensation at all for their pain and suffering consequent on the pre 2016 treatment they did have (see above re Interferon type treatments) in addition, they are having part of their compensation halved as a result of the supposed benefits of effective treatment (as defined by the Scheme) *which they did not receive*.

7.15.4 The effect is to penalise people with haemophilia (and others) who were infected, diagnosed and treated with Hep C last century for no reasonable reason.

7.15.5 Further, the Scheme fails to take into account that effective treatment as defined eliminates the Hepatitis C virus but doesn't reverse liver damage or treat symptoms such as fatigue and brain fog, neither does it reverse the past negative effect of Hepatitis C on earning ability which persists for those treated with Interferon type early treatments.

7.16 Impact on mental health and chronic fatigue

- 7.16.1 The impact on mental health and the chronic fatigue associated with living with these illnesses cannot be underestimated. When questioning the calculations of the various awards, the Society has been told that these have been captured in the core route and impact and autonomy awards. However, the Society does not believe that this is sufficient.
- 7.16.2 The core tariff route for many will compensate them for the impact of living with Hepatitis C however, as stated above, there is a group of people who have already been clinically assessed and approved that the impact of Hepatitis C went above and beyond the usual lived experience. The Society therefore wants that additional pain and suffering recognised.
- 7.16.3 The Society believes that one reason for this omission is that there was no psychologist included in the expert group appointed by the government with Prof. John Montgomery as Chair. As acknowledged by James Quinault in his evidence to the Inquiry on 8 May 2025, under the group's terms of reference they could not consult with the community nor was the community allowed to know the membership of this group. Not to have somebody with a deep understanding of the mental health impact of living with long term viral conditions was a serious omission. The Society believes that this has contributed to the undervaluing of the mental anguish and impact many people have lived with and is sadly a reflection that mental health is not valued as highly as physical health. Please see at Appendix [x], letter from Dr Sarah Helps, Interim Professional Clinical Lead - Infected Blood Psychology Service outlining her concerns in this regard.

7.17 Those bereaved on and after 1 April 2025

- 7.17.1 The Haemophilia Society calculated the total compensation and financial support available to a bereaved partner of someone mono-infected with Hepatitis C, and someone infected co-infected, depending on whether the infected partner died on or before the 31 March 2025 or on or after 1 April 2025. These calculations are provided at Appendix [x].
- 7.17.2 Under the England Infected Blood Support Scheme, the bereaved partner is able to continue receiving 75% of the annual EIBSS support payments that were being received by their infected partner. (CPI uprating in these examples is ignored as all figures are in 2025 value.)
- 7.17.3 The Society therefore submits that post 1 April 2025, bereaved partners should continue to be able to register for support payments as they were prior to that date.

7.18 Those who died young

- 7.18.1 Using IBCA's compensation calculator, the Haemophilia Society has estimated the compensation available to the estate of someone co-infected with Hepatitis C and HIV born January 1970, infected with Hepatitis C in 1979, infected with HIV in 1981 and diagnosed in 1984.

- 7.18.2 If that person died in 1992, their estate would be entitled to £1,023,966.47 in compensation. If that person lived until 2022 the compensation to their estate would be £1,954,626.47. This difference is mainly due to financial loss only being paid to people based on how long they lived. If the person was not married when they died then there is no compensation for financial loss after their death at all.
- 7.18.3 As stated in Andy Evans' evidence on 7 May 2025, "*Estate payments value being significantly lower than those which would have been received had the person lived, thus seemingly punishing those who have paid the ultimate price*".

7.19 Autonomy award

- 7.19.1 Many people with bleeding disorders who were treated with contaminated large-pool blood products do not feel that the autonomy award sufficiently compensates them both for the impact it had on their personal life and autonomy, and for the fact that they were treated inappropriately with concentrated blood products. The concentrated large-pool blood products such as factor VIII and factor IX used in the 70s and 80s were almost guaranteed to expose them to viruses and may have been unnecessary for their treatment. Their use in many cases ran counter to national and international guidance. These infection risks were known and not communicated to them; nor were they offered alternative treatments.
- 7.19.2 The Government Update on the Infected Blood Compensation Scheme – March 2025 said that the autonomy award "recognises the distress and suffering caused by the impact of disease, including interference with family and private life (e.g. loss of marriage or partnership, loss of opportunity to have children)." This is reflected in the Infected Blood Compensation Scheme regulations 2025 with payments of £40,000 - £70,000 under the autonomy award for surviving chronically infected people or the estates of those who have died.
- 7.19.3 The supplementary route increases these payments by an extra £10,000 for people with bleeding disorders who were treated at one of the haemophilia centres listed in the regulations and by £15,000 for people who were treated at Treloar's. This is to compensate for being used in "unethical research practices".
- 7.19.4 In the second interim report of the Infected Blood Inquiry (page 46) the autonomy award was described as follows:

c) an **Autonomy Award** as additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life, including where relevant: personal autonomy, loss of marriage/partnership prospects, loss of chance to have children. It should include sums for the aggravated distress caused by interferences in their autonomy and private life such as lack of informed consent, lack of sufficient information about the risks of treatment, and about diagnosis, treatment and testing, or being the subject of research without their informed consent. It should include the effects of lack of candour and inadequate responses by authority.

- 7.19.5 An extra £10-15,000 feels extremely low for all the experiences listed as causing the “aggravated distress” described above. The Society contends that people with bleeding disorders treated with concentrated blood products should all be in receipt of additional autonomy route compensation through the supplementary route. It also believes that the uplift for being the subject of research without their consent should be much higher than £10-15,000.
- 7.19.6 The Society also believes that the other aspects mentioned above such as lack of informed consent, inappropriate treatment with concentrated factor products instead of alternatives such as cryoprecipitate and lack of sufficient information about diagnosis, treatment and testing are not included in the core autonomy award or the supplementary autonomy award as described in the regulations. This should be remedied through changes to the supplementary route for the autonomy award to include compensation for this.
- 7.19.7 Confusingly the IBCA website says the Autonomy award “*recognises your loss of control over personal decisions, such as being able to have children, or being treated without knowing the risks.*” This seems to conflate these issues but may be reflective of the fact that it is not at all clear that the autonomy awards are correctly compensating people treated with concentrated blood products as was recommended in the second interim report.

8. Estates

- 8.1 Affected estates should be honoured. Those affected have now been informed that compensation is due to them however, due to the length of time that it is taking to set up and pay those infected and affected it will probably be years before they see this compensation. It is cruel for them not to know that even if they do not receive it in their lifetime, whether or not their families will be entitled to it and they can make provision for that.
- 8.2 To account for the above, the Society suggests:
 - 8.2.1 That individuals should be required to opt out of receiving financial advice as opposed to opting in – it should be a given that each individual will need to receive financial advice, or they should be given the opportunity to make the informed decision that they do not require such advice. This advice

should also include advice on avoiding falling victim to scams and improving personal security.

8.2.2 That inheritance tax advice is provided as part of the routine financial advice – particularly in relation to situations where the infected victim has died as has their spouse/partner so there is double intestacy.

8.2.3 That the cost associated with the making of a will should be covered

8.2.4 Dedicated will and probate specialist legal representation be made available to help with complex probate issues and potential mediation with families where estates have been entailed away from those closest to the original infected person. This should be made available to people even before asked to come forward for a claim to improve time from claim to payment.

9. Conclusion

9.1 In conclusion, the May 2025 hearings bore witness to an infected blood community united in the belief that: IBCA and the current Scheme do not deliver justice, there are victims who should be eligible for compensation who are excluded and others are undercompensated. The gaps and deficiencies need to be remedied or there is the risk of litigation. Everything should be done to avoid the need for individuals and groups to litigate: an ADR process for those who are falling through the gaps or not adequately compensated by the Scheme should be implemented without delay. Tariff bands should be developed so that awards can be tailored to individual circumstances. All of this work must be done with the community, not to it.

9.2 It is clear from the above, that the Society feels there are significant weaknesses in the compensation scheme as currently set up. However, it acknowledges that some minimal progress has been made and it is hoped that the most constructive way of progressing is to work with IBCA and the Cabinet Office to improve the current situation.

9.3 As ever, the Society is keen to share its knowledge and assist in any way it can, but things have to change. The defensive nature of the civil service has to stop as per Sir Brian's recommendation 5. The events of the past year evidence that this has not changed and the Society is concerned that unless there is a significant change in approach the situation will only worsen and continue to prolong the decades long fight that those infected and affected have had to endure.

23 May 2025

Katie Gollop KC

Serjeants' Inn Chambers

Eversheds Sutherland (International) LLP

Infected Blood Payment Scheme (NI)

**Consultation on enhanced support for
hepatitis C stage 1**

Department of Health (NI) Response

August 2022

Title: Infected Blood Payment Scheme (Northern Ireland) - consultation on enhanced support for hepatitis C stage 1 – Department of Health (NI) response

Author: Infected Blood Inquiry Team, Department of Health NI

Document Purpose: Targeted consultation – Departmental response

Issue date: 3 August 2022

Target audience:

- All beneficiaries of the Infected Blood Payment Scheme (NI);
- Patients infected by Human Immunodeficiency Virus (HIV) and/or hepatitis C through treatment with NHS-supplied blood or blood products;
- Family members of people infected by HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products;
- Spouses and partners bereaved as a result of infection with HIV and/or hepatitis C through treatment with NHS-supplied blood or blood products;
- Haemophilia Groups;
- HSC Trust Medical Directors (to be circulated to relevant clinical specialists working with hepatitis C patients, including NI Liver Trust and NI Regional Hepatitis B&C Managed Clinical Network);
- GPs (to be distributed through BMA);
- NI Mental Health Champion.

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Introduction

In March 2021, Health Minister Robin Swann announced plans to introduce enhanced financial support for eligible hepatitis C (HCV) stage 1 beneficiaries on the NI Infected Blood Payment Scheme.

This additional financial support, which is known as the 'Special Category Mechanism' (SCM) in England, 'enhanced hep C +' in Wales and 'severely impacted category' in Scotland, is intended to benefit hepatitis C stage 1 beneficiaries who experience ongoing physical or mental health symptoms related to multisystem complications arising from a history of HCV infection or its treatment.

This support was not previously available on the NI Scheme and in order to achieve greater parity across the UK, Minister Swann committed to the introduction of enhanced support payments for eligible HCV stage 1 beneficiaries, at the same rates paid in England, to be backdated to 1 April 2019. This was subject to an assessment process being developed, which Minister Swann committed to taking forward in consultation with key stakeholders.

A targeted consultation process took place from 6 December 2021 to 5 January 2022 to support the development of an eligibility assessment process that is fair and reasonable in the interests of achieving greater parity of financial support across the UK, whilst demonstrating proper accountability for public money. To support the consultation exercise, a working group was set up with membership including scheme beneficiaries, those infected and affected, clinical expertise and representatives of the relevant haemophilia organisations, as well as officials from the Business Services Organisation (BSO) and Department of Health NI (DoH NI).

The consultation response report is available on the Department of Health NI website at: www.health-ni.gov.uk/publications/infected-blood-payment-scheme-ni-surveys-and-consultations. Further background is available on the Department's website at: www.health-ni.gov.uk/consultations/infected-blood-payment-scheme-ni-consultation-enhanced-support-hepatitis-c-stage-1.

Department of Health (NI) response

The new HCV stage 1 (enhanced) payment is intended to provide additional help with living costs to improve quality of life for HCV (stage 1) scheme beneficiaries who experience ongoing physical or mental health symptoms related to multisystem complications arising from a history of HCV infection or its treatment.

To apply to receive these payments, the applicant must consider their HCV infection and / or its treatment to have a substantial and long-term adverse impact on their health and wellbeing, affecting their ability to carry out routine daily activities.

In developing a process to determine eligibility, the challenge was how to achieve an objective assessment of the impact of HCV infection on those stage 1 beneficiaries, while balancing that with the subjective nature of individuals' personal experience of living with the consequences of HCV and meeting the principles of managing public money.

Considerations

In deciding on the most appropriate assessment model for the NI Scheme, a number of factors were taken into consideration including feedback from the consultation.

The consultation process sought feedback from key stakeholders including those infected and / or affected and medical professionals. While the total of 61 responses was low, the feedback was helpful in building a picture of the various viewpoints on the issues raised.

Detailed analysis was carried out to compare the enhanced HCV support models in place in the schemes in England, Scotland and Wales and consideration of the advantages and disadvantages of those systems identified through feedback received in surveys and other correspondence.

It was also important to be mindful of the criteria for stage 2 payments on the Scheme, given that the stage 1 (enhanced) payment will be the same annual rate. To be eligible to receive the stage 2 annual payment, the beneficiary must have one of a number of conditions: cirrhosis, primary liver cancer, B-cell non-Hodgkin's lymphoma; or received a liver transplant / on the waiting list or Renal Disease due to Membranoproliferative Glomerulonephritis (MPGN). A comprehensive 16-page application form requires detailed information on medical history and a declaration by the stage 2 applicant's treating medical professional.

A further consideration was the purpose of the NI Scheme, which is to provide **ex-gratia financial support** for individuals and their families who have been infected / affected by HIV, HCV, or both, following treatment with NHS-supplied blood or blood products. The Scheme **does not provide compensation** for past harms. This is an entirely separate matter under consideration by Sir Robert Francis in his independent review and may be considered by the Infected Blood Inquiry, led by Sir Brian Langstaff.

To meet the principles of managing and allocating taxpayer's money responsibly in the public interest, the new model needed to be underpinned by a robust business case which highlighted any potential risks and provided evidence for how funding should be spent now and in future years. This was particularly pertinent in light of the October 2021 Renewable Heat Incentive (RHI) Inquiry Response Report.

Summary of NI model for HCV stage 1 (enhanced)

There are three criteria to be met to determine if a HCV stage 1 beneficiary is eligible for enhanced financial support:

- i. beneficiary experiences severe physical and/ or mental health symptoms which have an adverse impact on their quality of life;
- ii. symptoms prevent them from being able to carry out routine day-to-day activities, such as leaving home, using public transport, shopping, cooking or gardening;
- iii. symptoms are as a result of the residual impact of chronic HCV infection and/or its treatment.

The Health Minister Robin Swann has decided on a new NI model which is a hybrid of the systems in place in the other three UK schemes. It is designed to strike a balance between the subjective nature of individuals' personal experience of living with the consequences of HCV and the extent to which those symptoms impact on their everyday quality of life, with a more objective clinical assessment of the link to past chronic HCV infection as far as is possible, while meeting the principles of managing public money.

Name of new support

The new payment category on the NI Scheme will be referred to as **HCV stage 1 (enhanced)**. This is to avoid any ambiguity over the distinction between stages 1 and 2. The application process will be entirely paper based and there will be no requirement for an in-person medical assessment.

Eligibility

The NI Scheme will use the same list of conditions as the England Infected Blood Support Scheme (EIBSS) Special Category Mechanism (SCM) which was developed with support from an advisory group of clinical experts.

The purpose of applying this specific list of qualifying conditions is to assist with identifying HCV stage 1 beneficiaries who, as a direct result of HCV infection or treatment, suffer symptoms which have a significant adverse impact on their ability to carry out every day activities.

The EIBSS conditions to qualify for the SCM are those with pathogenetic data or other strong evidence of association with HCV, with the addition of mental health symptoms, persistent fatigue or other significant health and wellbeing impacts.

NI Scheme beneficiaries may be eligible to receive the HCV stage 1 (enhanced) payment if due to the impact of HCV and / or its treatment they:

- A.** have **autoimmune disease** due to or worsened by interferon treatment for hepatitis C (HCV), for example:
 - A1 Coombes positive haemolytic anaemia;
 - A2 Idiopathic fibrosing alveolitis of the lung;
 - A3 Rheumatoid arthritis.
- B.** have **sporadic porphyria cutanea tarda** causing photo sensitivity with blistering.
- C.** have **immune thrombocytopenic purpura**.
- D.** have **type 2 or 3 mixed cryoglobulinaemia** which is accompanied by:
 - D1 Cerebral Vasculitis;
 - D2 Dermal Vasculitis;
 - D3 Peripheral neuropathy with neuropathic pain.
- E.** are suffering from significant mental health problems, persistent fatigue and/or other health and wellbeing impacts due to HCV infection as a result of infected blood/ blood products, which affect the ability to perform daily tasks.

Criterion E

Criterion E was included in order to address a concern raised by some consultation respondents who believed that a narrow list of qualifying medical conditions may be too restrictive. Whilst criteria A – D will have clinical evidence recorded on patient medical records to determine eligibility, criterion E remains more subjective.

Therefore stage 1 beneficiaries applying under criterion E will be required to provide a short description of the condition(s) / symptom(s) (physical or mental) which adversely impact daily life and which they believe to be plausibly related to past HCV infection and/or treatment.

For medical professionals, this may require a degree of professional judgement and in some instances may require seeking further evidence from other medical professionals treating the patient.

There will be a separate declaration which has been designed to safeguard public funds whilst supporting clinical staff with a pragmatic approach to the subjective element in this criteria.

Self-assessment section

The NI Scheme will follow the precedent set by the Scottish Infected Blood Support Scheme (SIBSS) and Wales Infected Blood Support Scheme (WIBSS) whereby the applicant will be requested to self-assess their condition and its daily impact.

Applicants will be required to indicate on the application form if they suffer from one of the conditions listed (as detailed above), which are known to be caused by or directly linked to HCV, or if they suffer from significant mental health problems, persistent fatigue and/or other health and wellbeing effects due to HCV infection as a result of infected blood/ blood products, which impact on their ability to perform daily tasks.

Applicants will be required to indicate on the application form at what point following their infection with HCV the symptoms causing the additional difficulties began.

Guidance notes are included in the application form to assist applicants, including illustrative examples of what might merit eligibility for the enhanced support.

Medical professional section

There are numerous conditions associated with HCV and it can be difficult to establish with 100% certainty whether a condition is directly attributable to HCV or due to other risk factors or comorbidities. In order to appropriately safeguard public funding as well as provide a greater degree of consistency and reduce the likelihood of fraudulent applications, a supporting declaration by a medical professional will be required to determine so far as is possible a link to HCV infection and / or treatment.

The application form will include two separate medical professional declarations, depending on whether the beneficiary applies under criteria A – D or criterion E, where the medical professional declaration should be based on the information available and where there is no medical evidence to the contrary.

The declaration is a one-off requirement and supporting medical evidence will not be requested. GPs may claim for costs associated with the time taken to complete the form if they consider that this work is outside of the normal terms of the GP contract. Guidance notes are included in the application form (**annex A** – attached separately).

Application process

Written, online and e-mail versions of the application form will be available, to provide options for applicants.

The applicant will be required to complete sections 1 and 2 of the application form and must then pass the form on to a medical professional to complete section 3. Ideally the medical professional should be the clinician who is treating or has treated the applicant for the condition on the grounds of which they are applying for the enhanced support.

The form should then be sent directly by the medical professional to the Scheme Manager in the Business Services Organisation. The preferred option is for the application form to be sent electronically by scanning and e-mailing it from an official e-mail address. Alternatively, a hard copy of the application form with a hospital / GP practice stamp for verification may be sent by post.

The Scheme Manager is available to help with any queries. If the applicant is unable to secure completion of the declaration at section 3, they should return the form to the Scheme Manager who will provide advice. If an application is unsuccessful, there will be an opportunity to appeal the decision. The flowchart at **annex B** provides a summary of the application process pathways.

Independent medical panel

Under the EIBSS Scheme, all SCM applications are referred for a second stage of assessment by an independent medical panel. In order to ensure applications are assessed as soon as possible, it has been decided that the NI Scheme will not include this stage of assessment.

However, in instances where the medical professional feels unable to support their patient's self-assessment, applicants may be able to have their application referred to the EIBSS independent panel of medical assessors for completion of the medical declaration based on the information provided on the application form.

Three Year Audit

Once in receipt of HCV stage 1 (enhanced) payments, there will be no further re-assessment. However, the October 2021 RHI Inquiry Response Report stated that all government Departments must put in place systems to monitor schemes to ensure that implementation is working in practice especially when a third party is involved in implementing and/or administering the scheme or policy.

To meet this requirement, it has been agreed that an audit of all NI Scheme members will take place every three years.

This will be carried out by the BSO which administers the Scheme on behalf of the Department of Health (NI). Scheme beneficiaries **in all payment categories** will be required to sign a form to confirm whether there has been a change of circumstances including (in the case of HCV or HIV beneficiaries) whether their condition has deteriorated, improved or remains unchanged. There will be no requirement for medical professional verification.

Where a beneficiary notifies the NI Scheme that their condition has significantly improved, their annual payments may revert back to the standard stage 1 rate after a period of receiving the enhanced support, however there would be no question of basic stage 1 support ceasing.

If at any stage, a beneficiary has reason to believe they may no longer be entitled to receive the HCV stage 1 (enhanced) payment, they should inform the NI Scheme to ensure their annual payments revert to the standard stage 1 rate and that they are not overpaid.

The audit is a necessary means of ensuring records are up to date and accurate and that public funds are being allocated responsibly.

HCV stage 1 (enhanced) payments

The Department of Health and Social Care (DHSC) in England agreed to fund payments to support the introduction of enhanced support for Hepatitis C stage 1 beneficiaries backdated to 1 April 2019, up to the current 2022/23 financial year.

Going forward, there is limited funding available across all of health and social care in NI and it will not be possible to keep a permanent backdating policy in place. The NI Health Minister Robin Swann has therefore decided that a cut-off date of **30 June 2023** will be applied **for backdating** of any new eligible applications. Successful applications received after this date, will be paid from the date of the application.

Summary

There must be some means of measuring how beneficiaries fit into the various payment categories on the NI Scheme and whilst mindful of the suffering and distress beneficiaries have experienced, the Department must meet its obligation to take all steps required in managing and deploying public resources responsibly in the public interest and ensuring any new scheme is underpinned by a robust evidence base that can stand up to scrutiny now and in future years.

The agreed model is designed to place the greatest degree of control possible in the hands of the applicant, providing them with the opportunity to describe the impact on their daily life as it is acknowledged that they are best placed to assess this themselves. The supporting medical professional declaration is intended to help so far as is possible to determine the link to HCV and / or treatment, to provide the necessary assurances in terms of responsible management of public money as well as consistency in how applications are processed.

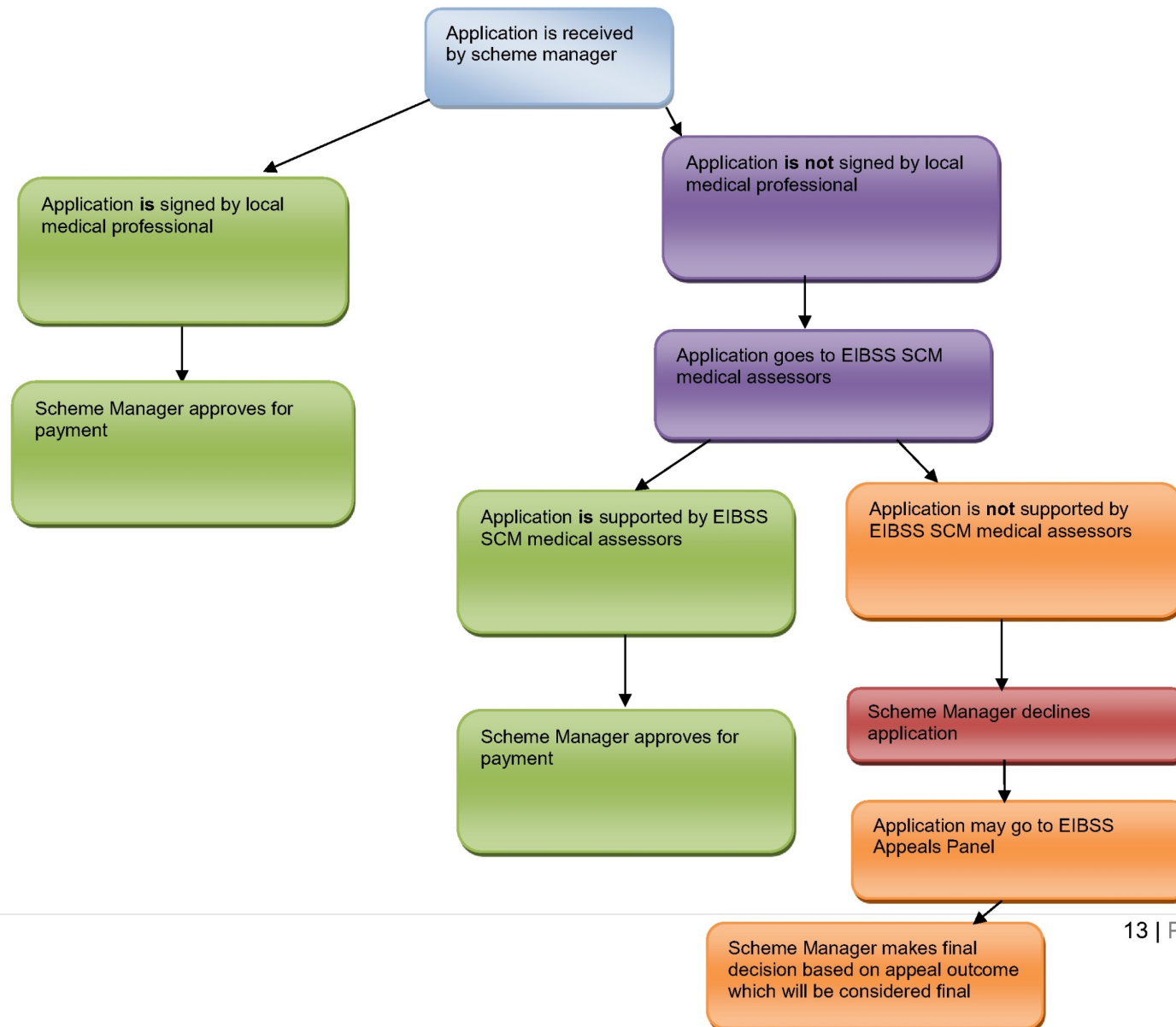
The Department will take steps to formalise the new policy and work with the BSO to implement the new financial support. The BSO will continue to monitor the new support to ensure it is operating as intended in practice and will address any issues or concerns which arise.

Application form

[PDF attached separately]

Infected Blood Payment Scheme NI HCV stage 1 (enhanced) support Application process

Annex B



Appendix 2 -

Using the example of some born January 1970, infected with Hepatitis C in January 1979 and diagnosed in 1984 the IBCA compensation calculator estimates they will receive £753,886.50 in core route compensation which will be adjusted to £509,189.98 if they chose to continue to receive their £35,327 per annum in support payments from the IBSS. Both compensation amounts include the £310,000 in interim compensation they should already have received.

Previously, in reliance on Appendix C of the August 2024 compensation scheme summary document, those on the SCM infected with Hep C expected automatically to qualify for supplementary route compensation.

The Haemophilia Society has estimated this supplementary amount to be £248,239.41 calculated as the difference between the same individual but increased to level 3 (cirrhosis). The total is due to an increased care award (adjusted £24,920.23 to £89,068.52) and financial loss award (adjusted £334,269.75 to £518,360.87).

Appendix 3

Infected Blood Psychology Service

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www.newcastle-hospitals.org.uk

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29.4.25

Statement of concern regarding Infected Blood Compensation Scheme Severe Health Award for people suffering severe psychological distress

The Infected Blood Psychological Service (IBPS) is finally being established across England to provide much needed specialist psychological care to people both infected and affected as a result of the Infected Blood Scandal.

IBPS operates separately from the Infected Blood Compensation Authority but is aware of the significant psychological impact of the compensation process on beneficiaries.

It is positive that past, present and future psychological sequelae of infected blood have been recognised within the core aspect of the Infected Blood Compensation Scheme. Within the scheme regulations, it is noted that psychological distress is not formally referred to but is alluded to within terms such as mental injury, emotional distress and injury to feelings.

The tariff-based core route is not designed to make provision for different levels of psychological distress. IBPS is therefore increasingly concerned that the supplementary route of the scheme does not adequately make provision for the full range of severe psychological distress experienced by both infected and affected people.

IBPS is concerned about the way in which the severe health conditions award of the supplementary route has been drafted in relation to mental distress. The severe health condition award indicates that this route can only be claimed if a person received psychiatric care lasting over six months which may have involved an in-patient stay.

However, IBPS believe that access to services would have been significantly impacted by issues such as a lack of understanding of the psychological and psychiatric sequelae of infected blood, stigma of accessing mental health services and indeed psychiatric service thresholds, leaving thousands of people without access to much needed care.

Furthermore, over past decades, beneficiaries are much more likely to have been assessed and treated by psychologists and counsellors in specialist services funded by Infected Blood Support services, rather than by core mental health services. It is these

professionals who would have assessed and treated the severe psychological harm experienced by beneficiaries.

It is unhelpful and unfair to expect a consultant psychiatrist to have provided a formal psychiatric diagnosis together with in-patient treatment, in order for supplementary compensation to be considered. We recommend that the severe health category is reworded to accept both a diagnosis made by a psychiatric professional *and* a formulation-based opinion of all qualified psychological and counselling professionals as supporting evidence of severe harm within a supplementary compensation claim.

To summarise, IBPS strongly recommends that the supplementary regulations are operationalised to allow for evidence from *any qualified doctor, counsellor or mental health professional* to support an application for the supplementary award related to severe mental distress.

GRO-C

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Appendix 4

Worked example - Partners of someone infected with Hep C

Someone whose partner was infected with Hepatitis C and died on/before 31 March 2025 remained able to register with EIBSS. Those partners will continue to receive £17,471 a year uprated by CPI for the rest of their life.

They would also be entitled to £62,000 in compensation as an affected person.

The estate of the infected person is entitled to £624,582 in compensation (including interim compensation payments).

Someone whose partner was infected with Hepatitis C and died on/after the 1 April 2025 is no longer able to register with EIBSS. That means that payments from the support scheme will stop on their partner's death.

The estate of the infected person is entitled to £624,582 in compensation (including interim compensation payments), the same as the example above.

They would also be entitled to £239,161 in compensation as an affected person which includes additional compensation for financial loss until their partner's healthy life expectancy.

Assuming the bereaved partner was the same age as their infected partner and the bereaved partner lives to healthy life expectancy this would give a total compensation and support package worth:

- £1,070,944 for the person whose partner died on 31 March 2025; and
- £863,743 for the person whose partner died on 1 April 2025.

Partners bereaved on or after 1 April 2025 are also left without additional financial support or compensation in the period between their partner's death and their claims for compensation being paid.