

Infected Blood Compensation Scheme Technical Expert Group

Roundtable background paper: Recognition of harm caused by interferon treatment

16 February 2025

This paper provides background on the Infected Blood Compensation Scheme structure, outlines the principles guiding the advice that the Infected Blood Compensation Scheme Technical Expert Group (TEG) has been asked to provide, and details the specific questions that will be discussed at the upcoming virtual roundtable.

Roundtable objective

The purpose of this roundtable is to facilitate targeted engagement with key organisation and charity representatives of the infected blood community to clarify evidence and test assumptions regarding the TEG's advice to the Government.

This roundtable focuses on the implementation of the Inquiry's recommendation in relation to recognising harm caused by interferon treatment.

1. Infected Blood Inquiry recommendation

In March 2025, the Infected Blood Inquiry announced its intention to publish an additional report to "consider the timeliness and adequacy of the Government's response on compensation". The Inquiry published its [Additional Report](#) in July 2025 which made a number of recommendations for the Infected Blood Compensation Authority (IBCA) and the Government in relation to the operation and design of the Scheme. It did not suggest that the structure of the scheme should be altered so its recommendations were for additions and modifications to 'build constructively on the scheme as it is' rather than fundamental change as this would cause inevitable delays in compensation being paid.

The Inquiry's Additional Report made the following recommendation in relation to interferon:

"People infected with Hepatitis B or C who have received a course of treatment with or based on interferon should be recognised as entitled to core awards at Level 3."

The Inquiry went on to say that treatment with interferon should be recognised through Level 3 or the introduction of a new infection severity band. The Inquiry said "*the choice –[Level] 3 or [Level] 2B – is for his [the Minister's] judgment*".

2. The role of the Technical Expert group and roundtables

The TEG has been asked to advise the Government on practical aspects of the recommendations made in the Inquiry's Additional Report. Decision-making on policy is a matter for the Government. The TEG is therefore concerned with:

- Identifying options for implementing the Inquiry's recommendations within this scope.
- Advising the Government on the practicalities and implications of each option.

In accordance with the TEG's [Terms of Reference](#), the group is able to undertake targeted engagement with members of the infected blood community in order to complete its work programme. This does not replace the formal public consultation that the Government has undertaken. Nor does it delegate the TEG's advisory responsibilities, for which it remains responsible and accountable. The TEG has had an opportunity to review the responses of the consultation using analysis from the Cabinet Office in order to structure the roundtable discussion.

This engagement will be focused on the scope of the Additional Report and has the following purposes:

- To enable testing of emerging TEG thinking, ensuring that the TEG advice is informed by lived experience and wider professional views
- To increase transparency about the TEG work process to ensure that the rationale and thinking in relation to all recommendations are available for scrutiny.

3. Roundtable format and process

Format: The TEG will convene a virtual roundtable to discuss an aspect of the Inquiry recommendations.

The first roundtables took place in December on the Special Category Mechanism (SCM). This roundtable will focus on recognition of interferon treatment within the scheme, and will inform the TEG's advice to the Government on this topic. The size of the group attending this roundtable is intended to enable a full and open discussion focussed on the TEG's work programme.

Further roundtables will be convened in the coming weeks to refine the TEG's initial advice on recommendations concerning severe psychological harm, the supplementary route for affected persons and extending the Special Category Mechanism (SCM) for the deceased. Each roundtable will be supported by a background paper on the specific recommendation to be discussed.

Attendees: The participants of this roundtable will be as follows:

- Chair - Professor Sir Jonathan Montgomery
- Approximately seven key organisations and charity representatives per roundtable
- Members of the TEG

- Cabinet Office officials will attend for the purpose of making a record of the meeting but are not part of the TEG.

Role of community participants: Following introductions, each community participant will have the opportunity to make a short statement of views before the questions identified by the TEG in this paper are raised. There will be no interruption to these contributions save to keep to the allotted time. The chair will then introduce the specific questions that have been identified in the paper and seek views on those questions if they have not already been stated. The aim is to ensure that each participant is able to contribute with an equal voice.

Where matters are raised that are outside of the scope of the TEG's terms of reference, this will be drawn to participants' attention.

Role of the TEG members: Following introductions, TEG members will be invited to listen without interruption or comment. Any questions (which are likely to be for clarification) will be raised via the Chair rather than from individual TEG members. The TEG Chair will endeavor to address questions from invited participants to the extent that they fall within the group's Terms of Reference. However, definitive answers may not be available until the TEG has concluded its work.

Written responses to the TEG: The TEG recognises that this issue affects a broad range of people across the community. In addition to the roundtables, the TEG invites written responses from key representatives in the community (see Annex A) to the questions in the background paper. This is separate to the consultation held by the Government. Responses to the TEG background paper can be sent to ibcs.teg@cabinetoffice.gov.uk.

So that responses can be considered ahead of the TEG's final advice, please provide written responses by **2 March (two weeks after the roundtable)**.

All responses from representatives will be shared with TEG members alongside a thematic summary prepared by the Cabinet Office which will be published at the conclusion of the series of roundtables.

Transparency: This paper is being made public as a commitment to transparency and will be provided to invited contributors ahead of the meeting.

Following the roundtable, a record of the discussion will be shared with participants to check for accuracy. Issues raised in written responses will be collated into a thematic summary that will be considered by the TEG. The record of the discussion at the roundtable and the report on written responses will be publicly released alongside the final report presenting the TEG's considered advice. Minutes of TEG meetings that discuss the roundtables and consider the written responses will also be published.

Confidentiality: For the purpose of transparency, a list of participants and a record of the key points discussed will be published, but it will not attribute opinions to specific participants. We hope this will help facilitate trust between participants and promote open conversation on sensitive topics.

The content, ideas, and key takeaways discussed during the roundtables can still be freely used and shared by participants; however attendees are asked not to disclose the identity or affiliation of the speakers.

4. Policy Background

This section outlines some key elements of the Compensation Scheme that provide the context for the TEG's work programme. The TEG will aim to give advice that builds on the fundamental structure of the Scheme.

4.1 Compensation scheme structure

The Infected Blood Compensation Scheme adopts the five heads of awards for infected people proposed by the Inquiry:

- **Injury award:** This award recognises the physical and mental injury, emotional distress and injury to feelings that may have been caused or will in future be felt as a result of: infected blood and/or related medical treatments; the death of an infected person; the likely death of a loved one in the future.
- **Social Impact award:** This award recognises the past and future social consequences that people with blood-borne infections may have suffered (e.g. stigma and social isolation).
- **Autonomy award:** This 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).
- **Care award:** This award recognises the past and future care needs and associated costs for infected people.
- **Financial Loss award:** This award recognises the past and future financial losses suffered as a result of infection. This includes both financial loss and loss of services (e.g. providing childcare).

The Scheme has two routes: the **core route** (offered to everyone eligible) and the **supplementary route** (for exceptional cases where greater compensation for financial loss and care costs is necessary).

The reports from the previous [Infected Blood Inquiry Response Expert Group](#) advised on the amounts that would be indicated by reference to judicial guidelines and court decisions, although not limited by them.

A full overview of the scheme can be accessed [here](#). A high level overview of the scheme can be accessed [here](#) (please note this does not reflect the amendments from the third set of regulations).

4.2 Recognition of interferon in current scheme

Most infected people who have been treated with interferon are currently eligible for compensation in line with the Level 2 Hepatitis (chronic) severity band.

The Level 2 band was designed to provide compensation for the conditions and other effects on their life that people with a chronic Hepatitis infection would commonly experience,

including treatment with interferon. The calculation of injury awards for chronic hepatitis was made by reference to judicial guidelines relating to cases that included chronic fatigue and cases from earlier litigation in relation to receipt of infected blood that had involved interferon treatment.

Care awards for those at Level 2 were assessed on the basis that most people with chronic hepatitis would need ten years of domestic support. While actual needs will vary for individuals, the scheme is based on providing an annual sum calculated to fund an average of six hours support per week to help with heavier domestic tasks, attending medical appointments, and household maintenance. No evidence is required that this support was needed or paid for.

Level 2 financial loss awards are calculated on the assumption that a person's ability to work would be reduced by 40% (this equates to only being able to work part-time for three days per week, for example, or the equivalent in reduced daily hours).

It is known that some people suffer severe medical complications from interferon treatment, including autoimmune diseases. These will result in a significantly greater loss of earning capacity than recognised in the core awards and the scheme assumes that this would amount to a 70% loss. A number of the 'severe health conditions' recognised in the scheme are specifically linked to the consequences of interferon treatment.

4.3 Government response to Inquiry's recommendation

The Inquiry's Additional Report suggested that the Level 2 severity band does not provide enough compensation to fully recognise the impact that treatment with interferon had on infected people. The Inquiry recommended that people infected with Hepatitis B or C who have received interferon treatment should be entitled to higher compensation under the core route, and that it would be a choice for the Minister to decide whether to uplift to Level 3 severity band or to create a new Level 2B band.

In response, the Government proposed to introduce a new Level 2B severity band that would give more compensation to recognise the impact of interferon treatment. The Level 2B band would provide core awards higher than Level 2 Hepatitis (Chronic) and lower than Level 3 (Cirrhosis). The Government worked with advice from the TEG to develop a proposal that was outlined in the public consultation that ran between October 2025 and January 2026.

4.4 Technical Expert Group Advice

The TEG supported the Government to develop the Level 2B band proposal by providing advice in two primary areas:

The impacts of interferon

- **Short-term impacts (lasting less than 2 years):** The TEG looked at evidence of the short-term side-effects of interferon treatment. This included guidance from the [National Institute for Health and Care Excellence \(NICE\)](#), which suggests that many, but not all, people find interferon alpha therapy very hard to tolerate. The guidance

notes that a large number of patients experience flu-like symptoms after each injection, and up to half may suffer from chronic fatigue, headaches, fever, muscle aches, insomnia, and nausea. It also notes that around a quarter of patients report hair loss, joint pain, chills, irritability, itching, depression, skin rashes, and a decreased appetite, and that such side effects frequently lead to patients stopping or not adhering to treatment. While depression is a known risk of interferon treatment, studies suggest these symptoms typically resolve quickly once treatment ends.

- **Long-term impacts (lasting more than 2 years):** The TEG considered the available evidence on long term side-effects of interferon treatment. It noted evidence from infected people to the Inquiry of their experience of significant longer term impacts. It also noted that the Infected Blood Inquiry's Hepatitis Expert Group had found no predictable long-term side effects of interferon in the available clinical trial data. The TEG recognised that this clinical trial data had limitations. It anticipated that the Government's public consultation would gather experiential data to shape its final proposal.

Award level and values

- **Level 2B:** The TEG advised that the Level 2B proposal should provide compensation for the short-term side effects of interferon treatment, with any long-term effects better addressed through the proposed supplementary Severe Health Condition awards.
- **Duration:** The TEG advised basing the award on an average treatment period of **48 weeks**. This advice was based on relevant NICE guidance and the Infected Blood Inquiry's Hepatitis Expert Group report. Although people undergo interferon treatment for different lengths of time, setting a 48-week period was advised to minimise the evidentiary burden on claimants. In some cases, this means people will receive compensation for 48 weeks even if their actual treatment was shorter. The TEG advised that short trials of treatment, less than 12 weeks, should not create eligibility for a Level 2B awards as the cessation of treatment would have meant that effects were short-lived. However, it noted that this might be difficult to demonstrate and suggested that these evidential issues might be explored via the Government's consultation.
- **Award levels:** The TEG provided advice on the appropriate award values for a Level 2B severity band, considering the impact of treatment and associated side effects.
 - **Care Awards.** It considered that during the year in which treatment was received the care award should reflect the likely need of 16.5 care hours per week (described as 'low care' in the compensation scheme). It considered that in years after treatment with interferon had finished that the provision of 'domestic support and ad hoc care' that was already made for those with chronic hepatitis was likely to be a reasonable level for the care award.
 - **Financial Loss.** The TEG considered that during the year of treatment and for the year following those who received interferon treatment would have considerably greater loss of earning capacity than people with chronic hepatitis who did not receive such treatment. The TEG suggested that for this

two year period financial loss should be aligned to that of Level 3 (Cirrhosis) at 80%. It considered that after this two year period, the longer term impacts of interferon treatment were likely to be reduced and that a 40% loss of earning capacity, as recognised in the Level 2 Hepatitis (Chronic), was a reasonable recognition of the likely financial loss.

4.5 Government proposal

Taking into account TEG advice, the Government's proposal for Level 2B, as set out in the consultation, was as follows:

Eligibility

All infected individuals who have received treatment with interferon would qualify for the Level 2B infection severity band as part of their core compensation award.

Award levels for Level 2B

- Injury award:** A £10,000 uplift on the Level 2 band, bringing the total value of the core route injury award for interferon recipients to £70,000.
- Financial Loss award:** Compensates for a higher level of financial loss for two years (the year of treatment and the following recovery year). It assumes earning capacity was reduced to 20% during this time. The total value of the award would be £23,726 per annum (80% of UK median salary plus 5%) for those two years.
- Care award:** Provides one additional year of low-level care (16.5 hours per week) compared to the Level 2 band. People treated with interferon would automatically qualify for this uplifted care award without needing to provide further evidence.

How Level 2B compares to awards made under the current severity bands

- For people currently eligible for Level 2 (Chronic Hepatitis): More compensation for injury, financial loss, and care.
- For people currently eligible for Level 3 or 4 who were treated with interferon **before** developing cirrhosis: More compensation for financial loss, no change to injury and care awards as the current band already compensates for the types of physical and mental harm that may be caused by interferon treatment.
- For people currently eligible for Level 3 or 4 who were treated with interferon **after** developing cirrhosis: No change to the compensation award, as the existing band already covers the physical and mental harm that may be caused by interferon treatment.
- For people co-infected with HIV and Hepatitis (at any infection severity band): No change to the award as the compensation entitlement already covers the physical and mental harm that may be caused by interferon treatment.

The consultation asked:

1. *Do you think there are short term side-effects (lasting less than 2 years) of interferon treatment that we have not taken into account in this proposal?*
2. *What short term side-effects (lasting less than 2 years) do you believe have not been covered by this proposal? We welcome evidence to support your response to this question and any detail you can provide about how these side-effects affected your care needs and ability to work over a given duration.*
3. *Do you think there are long term side-effects (lasting more than 2 years) of interferon treatment that are not fully covered by the proposed Severe Health Condition award?*
4. *What long term side-effects of interferon treatment (lasting more than 2 years) do you believe have not been covered by the Severe Health Condition award? We welcome evidence to support your response to this question and any detail you can provide about how these side effects affected your care needs and ability to work over a given duration.*

4.6 Principles of evidence to support a tariff based scheme

The TEG will apply the principles of evidence that were identified in its predecessor's work in order to promote consistency. These principles are:

- **Accessibility:** Accessible to claimants (and assessors) means that only information that is reasonably expected to be available if requested should be sought to establish eligibility.
- **Assessability:** Evidence must be suitable for use by the Infected Blood Compensation Authority (IBCA) to determine eligibility or entitlement without significant further inquiry or assessment in line with principles of a tariff based scheme.
- **Verifiability:** Evidence must be verifiable to maintain the integrity of the scheme.
- **Proportionality:** No more intrusion into people's privacy should be sought than is required to ensure that they receive the compensation to which they are entitled.

4.7 Review of issues raised in consultation responses

The Government will consider all responses submitted to the public consultation and will publish a response within 12 weeks of its closing. The work of the TEG in advising the Government is separate from this process. However, the TEG has asked for an indication of the points raised in response to two of the consultation questions. This is so that the TEG can consider whether the issues raised should lead us to advise that the Government amend the proposal outlined in the consultation.

TEG advice will be only one aspect of the considerations that the Government will take into account. We have therefore considered what our approach should be as a 'technical expert group' when the evidence about the impact takes many different forms, including lived experience, clinical trials, reports in professional literature. We intend to be transparent about the basis, and therefore also the limitations, of our advice. In the following paragraphs

we set out our tentative view of the proper role of the TEG. We may refine this in the light of the discussions at the roundtables and associated written submissions.

The TEG will discuss the lists of short term and long term impacts identified in the consultation responses and consider whether it is able to say (a) whether it is more likely that they were caused by interferon treatment than by the underlying infection or whether it is likely that they were caused by some extraneous factors; and (b) how common it was to experience these impacts. It will also consider the strength and limitations of the available evidence in addressing these questions.

For those conditions where it is likely to have been caused by the underlying infection, then the TEG thinks that they should be part of the core award for chronic hepatitis infection. It will therefore consider whether that core award adequately reflects them. Where they are likely to have been caused by interferon treatment, then this should be recognised as part of the proposed new interferon award. For those cases where the impacts were uncommon but severe, then the TEG will consider whether they are covered by an existing severe health condition, and if not, whether a new category is required.

5. Roundtable discussion

As well as hearing from participants, the TEG is seeking a fuller understanding of how the scheme might be adapted to address the concerns raised in the Additional Report in a way that is consistent with the structure of the scheme and the evidential challenges presented by lack of records and uncertainty over what causes impacts. We have identified some specific questions on which we could welcome views.

Questions for the roundtable:

1. What issues arise from the proposal for a Level 2B band rather than a move to Level 3 for all those who were treated with interferon?
2. Is the 48-week standardised treatment period an appropriate rule to minimise the burden of proof?
3. What evidence of interferon treatment is likely to be available in order to ensure that people will be able to demonstrate eligibility?
4. Was it common for people to need to purchase care for more than 16.5 hours per week during their course of treatment?
5. Are the assumptions regarding financial loss (reduction to 20% earning capacity for two years and a reduction to 60% thereafter) reflective of the lived experience of the majority of interferon patients?
6. Would supplementary awards for people with long-term psychological harm better recognise those with permanent side effects than a specific interferon-related award? This could remove the need to consider whether the harm was caused by interferon treatment or by the infection.

Next steps

A record of the meeting will be drawn up by the Cabinet Office and circulated to all attendees to check for accuracy. This will be made public alongside the advice from the TEG. Written responses will be collated and reported to the TEG. This will also be made public alongside

the advice from the TEG. The TEG will discuss what it has learnt alongside other information, including relevant responses to the Government's consultation. A minute of these discussions will be published alongside its advice as with all TEG meetings.

The TEG may approach individual participants for further clarification of points raised. If this happens, the focus and outcomes of such exchanges will be recorded in an agreed note that can be made public alongside the advice from the TEG.

Annex A:

List of key representative organisations and charities in the infected blood community whom are invited to comment on the background paper via correspondence.

- [The Birchgrove Group](#)
- Blood Friends (formerly North West England Support Group)
- [Bloodloss Families](#)
- British Liver Trust
- [Contaminated Blood Campaign](#)
- Contaminated Blood Women
- [Contaminated Whole Blood](#)
- [Factor 8](#)
- [Families of Deceased Infected Blood Victims UK](#)
- [The Fatherless Generation](#)
- [The Forgotten Few](#)
- Former Treloar's School Pupils
- [Friends and Families of Haemophilia Northern Ireland](#)
- Haemophilia Action UK
- [Haemophilia Northern Ireland](#)
- [Haemophilia Scotland](#)
- [Haemophilia Society](#)
- [Haemophilia Wales](#)
- [Haemosexual](#)
- [The Hepatitis B Trust](#)
- [The Hepatitis C Trust](#)
- Individual campaigner for estates, women and carers
- Manor House Group
- Mono-HCV Infected Haemophiliacs
- Positive Women
- Misdiagnosed Victims
- [Scottish Infected Blood Forum](#)
- [Terrence Higgins Trust](#)
- [UK Thalassaemia Society](#)
- [Tainted Blood](#)
- Tainted Blood Parents

- Tainted Blood Widows and Bereaved Partners
- Independent Widows
- HaemAffected
- Independent Longstanding Campaigners