Cabinet Office

Government response to consultation on proposed changes to the infected blood compensation scheme

14 April 2026

CP 1565

Government of the United Kingdom

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Government response to consultation on proposed changes to the infected blood compensation scheme

Presented to Parliament
by the Minister for the Cabinet Office
by Command of His Majesty

April 2026

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Government response to consultation on changes to the Infected Blood Compensation Scheme

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Foreword by the Minister for the Cabinet Office

The infected blood scandal is a systemic failure that has had a profound and lasting impact on the lives of thousands. For decades, infected and affected people have fought for recognition and redress. This Government remains resolute in its commitment to provide compensation for every victim of the infected blood scandal.

I would like to acknowledge the work of Sir Brian Langstaff and the Infected Blood Inquiry ('the Inquiry') team as these proceedings reach their conclusion. I am grateful for the thorough manner in which the evidence was examined and the recommendations they made to the Government. The completion of the Inquiry's mandate is a significant and necessary step.

When we opened this consultation, we did so with a clear objective: to ensure that the Infected Blood Compensation Scheme ('the Scheme') is robust, fair, and capable of meeting the diverse needs of the community it serves. I am deeply grateful to everyone who took the time to respond. I thank in particular the members of the infected blood community, whether infected or affected, and the charities and other representative organisations who shared their views. I recognise that participating in this process may have involved revisiting memories of events that had a profound and traumatic impact. The impact of these events may not only be in the past, but a present and lived reality for so many. I am especially conscious of the particular effort required from those who responded whilst contending with their own ill health, and for that I am profoundly grateful.

Every response to the consultation has been considered carefully. Every answer has formed part of the analysis that underpins the response set out in this document. Your contributions have been invaluable in helping us refine the Scheme to better meet the recommendations of the Inquiry.

In response to the consultation, we are taking a number of definitive steps to ensure the Scheme functions effectively. We understand that every day waiting for compensation is a day too long. My priority has always been to ensure that the Infected Blood Compensation Authority (IBCA) has the tools to deliver compensation as swiftly and sensitively as possible. A key priority is the formalisation of the Scheme through the necessary legislation, which will grant IBCA the full mandate required to continue its operation without further delay.

No amount of financial compensation can ever fully atone for the losses suffered. However, this response marks a significant milestone in our efforts to provide meaningful resolution. I would like to thank everyone who has contributed to this consultation. Your engagement has ensured that the Scheme is built upon the lived experience of those it is intended to support.

This document sets out the Government's response to the consultation. We have listened carefully to the feedback provided on the proposed changes to the Scheme and, alongside IBCA and the Technical Expert Group (TEG), we have used those consultation responses to finalise the Scheme's design.

The consultation process provided valuable insight and we have sought to ensure that the final changes to the Scheme directly address the issues identified as most important by respondents. This response to the consultation sets out how these contributions have shaped the Scheme, ensuring that the measures implemented are both practical and responsive to the concerns raised by those impacted.

The Rt Hon. Nick Thomas-Symonds MP
HM Paymaster General & Minister for the Cabinet Office

Acknowledgements

We would like to express our profound gratitude to every person who took the time to share their views and experiences in response to this public consultation. We recognise that many people have an interest in the compensation scheme and valuable ideas to tell us about how it should change, whether they are directly infected or affected, know someone who is, or simply feel that justice is due to those who are.

We recognise that for many members of the infected blood community, the process of recounting personal experiences or the lived experiences of loved ones is deeply painful. We do not underestimate the emotional toll that many members of the community have endured to support us with this consultation and help shape the Scheme. We have carefully read and considered every response received.

A Note on Language

Many of the responses to the consultation convey the significant distress and suffering that victims of the infected blood scandal have endured and continue to endure. We do not intend to trivialise the deeply personal and difficult realities faced by many in the language we use in this response document. At times, clinical or legalistic terminology is used which we recognise will not always reflect the reality of the lived experience that we know sits behind every response. It is, however, important for the Government to use recognisable clinical markers for the purpose of developing the legal and administrative frameworks required to deliver a robust and fair compensation scheme.

Data Privacy and Confidentiality

We recognise that the experiences of people in the infected blood community are both private and sensitive. Despite this, they have not always been treated with dignity and respect.

Because of that, some people may feel concerned about how their personal information has and will be handled. Any information shared as part of this consultation will remain private and confidential. All personal information is being handled in accordance with data protection legislation, including the UK General Data Protection Regulation and Data Protection Act 2018. The Privacy Notice for this consultation provides further detail on how data is handled.

We will not publish individual responses to this consultation. Individuals or organisations may independently choose to publish the response they submitted to the consultation. There are occasions where we have attributed certain parts of a response either to a charity or a Recognised Legal Representative (RLR).[1] We have sought direct permission in these cases to attribute the quote to them.

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[1] Recognised Legal Representatives are solicitors approved by IBCA who can provide applicants to the Scheme with independent advice which is paid for by IBCA.

Executive Summary

In July 2025, the Infected Blood Inquiry ('the Inquiry') published its Additional Report on Compensation. It made a number of recommendations for the Government on ways it felt the compensation scheme could be improved so that it better met the community's expectations, and experiences.

We were in a position to immediately accept - and address - some of these recommendations. These regulatory changes came into force in December 2025. As a result of these changes:

- Anyone infected with HIV as a result of infected blood treatment received before 1st January 1982 is now eligible for compensation.
- There is no longer a minimum earnings threshold for a person to claim the Exceptional Loss award. This provides a route for people who did not benefit from effective treatment to apply to have their financial loss fully recognised. This change also means that anyone who has evidence of actual earnings can apply for this route without needing to show they meet the threshold.
- The provisions that IBCA use to assume infection progression where someone lacks evidence have changed to ensure that anybody with a Level 4 Hepatitis infection will also be compensated for the period that they will likely have spent with a Level 3 infection, regardless of when they were diagnosed with a Level 4 infection.
- A date of diagnosis for Hepatitis B and C no longer has to be provided when applying for the Scheme.
- Estates of people who died between 21st May 2024 and 31st March 2031 are now eligible to apply for compensation.

On the remaining recommendations, we were either advised by the Inquiry to consult the community, or felt that doing so would be the best way to make sure our proposals reflected the community's views on how the Scheme could best be changed. The consultation was open for responses for 12 weeks, from 30 October 2025 to 22 January 2026.

We have now carefully considered every response to the consultation. Where relevant, we have also asked for further advice from the independent Infected Blood Compensation Scheme Technical Expert Group (TEG) to help us finalise the changes to the Scheme. Separately, since the consultation closed, the TEG has undertaken targeted engagement sessions with key organisations and charity representatives of the infected blood community. These sessions, which have focused on the different topics included in the consultation, have been used to help inform the TEG's advice to the Government on changes to the Scheme. The TEG will publish its final report on 14 April 2026.

Summary of consultation response

What we have heard through the consultation has allowed us to now set out how the Scheme will change in response to the Inquiry's recommendations.

In two areas, we explained in the consultation that we were unable to find a way to implement the Inquiry's recommendations but wanted to hear the community's views on how this might be done. We are now in a position to make changes to the Scheme in the following areas as a result of what we heard:

Affected Supplementary Route

In the consultation, we explained that we had been unable to find a fair way of introducing additional supplementary compensation for affected people and invited respondents to tell us how they thought we might do this, including what they thought about giving certain groups of affected people more compensation.

Following the consultation, we are introducing a 50% uplift to the core Injury award for some affected people. Eligible bereaved parents whose infected child died under the age of 18 will receive an uplifted Injury award to recognise the profound impact of this loss. Eligible bereaved partners will also receive an uplifted Injury award to recognise the deep emotional harm of losing a partner. Growing up in a home or family impacted by infected blood meant that people's life paths were permanently changed. For this reason, children and siblings of infected people who were affected whilst they were under the age of 18 will also receive an uplifted Injury award, calculated based on the highest severity of infection they experienced during childhood.

Exceptional Loss award

In the consultation, we explained that we had been unable to find a fair way of recognising people's loss of potential, where they lacked actual evidence of their earnings but where there was nevertheless a clear chance that they would have gone on to earn at a high level.

Following the consultation, we are introducing a compensation uplift of £60,000 for people who had entered, or had an offer to enter, a higher-earning career but were unable to progress in this career due to their infection. This award will be available through the supplementary route and will come in addition to Financial Loss awards paid through the core route. People will not need to show an actual salary offer or earnings, instead IBCA will determine whether a given career would have generally paid at least 10% higher than the gross national median average earnings. If so, a person would automatically be eligible for the £60,000 award.

Otherwise, the Exceptional Loss award will continue to be available through the supplementary route for people who can provide evidence of earning more than the core route before they were infected. We understand from the consultation that some people are concerned that they will not be able to access this award if they do not have historic payslips. We will work with IBCA to ensure that communications are clear about the broad range of alternative evidence that people could use to show they are eligible for the Exceptional Loss award so that this is not a barrier.

In four areas, we will make additional changes to the proposal we originally set out in the consultation document. We are making these changes because respondents told us how our proposal could be expanded or amended to best meet the community's expectations:

Special Category Mechanism

We will make sure that everyone who was eligible for SCM or an equivalent payment through the Infected Blood Support Schemes (IBSS) receives additional financial loss and care compensation so that the existing acknowledgement of the impact their infection had on their day-to-day life is properly compensated. Following the consultation, we agree that everyone in this position should have the award fully backdated to 2017 (when the SCM award was first introduced) regardless of when they were assessed. We will make sure that living people who were not given a chance to apply for SCM can apply for it through the Scheme.

Interferon

As proposed, we will introduce a new 'Level 2B' award so that people who suffered from the side-effects of interferon treatment receive an additional Injury award, as well as further financial loss and care compensation, to reflect the impact it had on their lives. Following the consultation, we will also make sure that people who received more than one round of interferon will be properly compensated for each of these rounds.

Past Financial Loss and Past Care awards

As we proposed, we will remove the 25% deduction applied to past Care compensation for people who choose to receive support scheme payments for life. Following the consultation, we will make sure that people receive past Financial Loss compensation based on whichever of the two ways to calculate this award is most financially beneficial for them.

Unethical Research award

As we proposed, we will change the eligibility criteria so that everyone treated for a bleeding disorder within a specific time period will receive an unethical research award. They will no longer need to prove that this treatment happened at a specific haemophilia centre, or that they were part of a specific research trial. Following the consultation we will adjust the date range to make sure it captures the evidence of unethical research that respondents shared with us.

We will also introduce a new Unethical Research award for children. This means that people who were treated for a bleeding disorder in childhood will receive a higher Unethical Research award than those who were treated in adulthood.

Overall, we will increase the amount of compensation that all eligible people receive for unethical research. People who attended Treloar's will receive £60,000, rather than the £25,000 proposed in the consultation. Other children will receive £45,000. And those treated in adulthood will receive £30,000, rather than the £10,000 they receive currently.

In the following area, we will implement the exact proposal we initially set out in the consultation, because the proposal responds to people's concerns about how the Scheme recognises their mental health concerns, and is underpinned by expert clinical and legal advice from the TEG:

Severe Psychological Harm

In the consultation we explained that we thought the new proposal on SCM would provide a further route for people experiencing psychological harm to receive more compensation. We explained that we thought it allowed people who had experienced more psychological harm than the core route assumed, but less than those with the very severest harm (for whom the existing Severe Psychiatric Conditions award exists) to receive more financial loss and care compensation to account for the impact that this harm had on their life.

Following a review of the consultation responses, we will introduce the new SCM proposal and therefore welcome supplementary route applications from those who can show that their circumstances require more financial loss and care compensation for psychological harm.

In addition, it was clear from the consultation that many people felt that the Scheme did not go far enough to reflect the profound impact of infection for those who were infected in childhood, whether they were infected or affected. People affected as children will receive an uplifted Injury award, as set out above. We will also address this through a new change to the Scheme, set out below:

People infected as children

People who were infected when they were aged 18 or under will receive a 50% uplift to their core Autonomy award, calculated based on the highest severity of infection they experienced during childhood.

What these changes mean for applicants

We know some people reading this response will be interested in exactly how we have responded to each recommendation. Others will be interested to know how the changes, all together, mean theirs or their loved one's compensation awards may change.

Infected people will receive increased core awards. Anyone who chooses the 'IBSS route' for their compensation will receive a higher Care award, because we are removing the 25% deduction applied to past care costs for people who choose this route. People who choose the IBSS route will also receive past Financial Loss compensation that reflects the higher of two calculations that could be used to calculate their loss. Anyone who was treated with Interferon but whose infection has not progressed to the Level 3 severity band will receive a higher injury award, and more financial loss and care calculation. People infected as children will receive a 50% uplift to their core Autonomy award, to recognise the loss of potential that the infection will have caused.

Infected people will also be able to apply for more supplementary awards, and some of these supplementary awards come with increased compensation. Any infected person who received treatment for a bleeding disorder in the UK before 1986 will receive an additional Autonomy award. Those who attended Treloar's will now receive £60,000. For the first time, children who did not attend Treloar's but were treated in childhood will receive an increased award of £45,000. Those treated in adulthood will now receive £30,000. The new supplementary route award to compensate people who are eligible for SCM or its equivalents will mean the scheme better recognises the impact of Hepatitis B and C infections on day to day life, including the psychological distress and harm caused by the infection or treatment for the infection. As well as compensating people who have actual evidence of high earnings, we will award more compensation to people who can show that they had recently started or been offered a job where the median salary is more than 10% higher than the national gross median, were it not for the infection preventing them from taking up a job.

Changes to the core route compensation for infected people will mostly make a difference to the compensation that people with Hepatitis B and C receive. Many of the changes to the supplementary route will also lead to more compensation for those with Hepatitis B and C, where they are eligible. Infected children - regardless of the nature of their infection - will receive more compensation and those treated in childhood for a bleeding disorder will receive a higher Unethical Research award. Wider changes to the supplementary route will mean that all infected people - regardless of their infection severity or type - will be able to apply for additional compensation.

Some affected people will receive uplifts to their core award compensation. To better recognise the psychological harm that infection caused for some affected people, we will introduce new, increased Injury awards for parents who suffered the unimaginable loss of a child dying due to infected blood before they were 18, for the partners of deceased infected people, and for affected people whose own childhood and potential was affected by what happened.

Understanding the compensation scheme

We recognise that the Scheme is complex and elements of it can be difficult to understand. To help with this, we have separately published a guide explaining the most important things about the Scheme and the way it is designed. The guide also addresses some common queries raised about the Scheme in people’s responses to the consultation. We encourage people to read this guide alongside this document, as it gives important context to the changes we are now making to the Scheme.

We hope that the final policies set out in this document demonstrate our commitment to bringing long-awaited justice to the victims of the infected blood scandal and to enabling fair compensation to be paid as swiftly as possible while, as far as possible, minimising the burden on people applying.

In finalising its policies, as set out in this response, the Government has complied with its responsibilities under the Equality Act 2010.

Overview of Responses to the Consultation

The consultation was published on GOV.UK and was open for responses for 12 weeks from 30 October 2025 to 22 January 2026. The majority of responses were submitted via an online survey platform, SmartSurvey. We also accepted responses sent by email or by post (though no responses were received by post).

The consultation received 710 responses. The table below provides a breakdown of the number of responses received by each category of respondents, if they chose to provide this information.

Category of respondent	Number of responses per category
People who are living with or have previously had an infection (as a result of indirect infection or treatment with infected blood or blood products)	292
People who have been affected (as a result of another person's infection due to indirect infection or treatment with infected blood or blood products)	312
People who are both living with or have previously had an infection due to infected blood or blood products **and** have been affected as a result of another person's infection	40
People who are neither an infected or affected person, but have an interest in the Infected Blood Inquiry	27
None of the above	6
Prefer not to say	7
26 respondents chose not to answer the question	

Section 1: The Special Category Mechanism and its Equivalents

Inquiry recommendation: *"The Government reconsider whether to maintain its rejection in February 2025 of the recommendations of Sir Robert Francis KC and advice from the Infected Blood Inquiry Response Expert Group of August 2024, which was expressly accepted at the time by the Government, to introduce (as one of six health impact groups which would justify a severe health condition award) the following for people infected with Hepatitis B and Hepatitis C:*

'Other Hepatitis C associated extra hepatic disorders resulting in long-term severe disability. This includes those currently assessed as the following category on IBSS:

- Hepatitis Special Category Mechanism (EIBSS)
- 'Severely Affected' Hepatitis C (SIBSS)
- Hepatitis C Stage 1 Plus (WIBSS)
- Hepatitis C Stage 1 Enhanced Payments (NIIBSS)'"

Summary of consultation responses

Question one asked whether *respondents agreed that infected people who had been assessed as eligible for SCM (or its equivalents) by one of the Infected Blood Support Schemes should automatically qualify for an additional award.*

447 respondents chose to answer this question. Of these respondents, 398 (89%) said they agreed with the proposal. 17 (4%) said they disagreed with the proposal. 32 respondents (7%) said they did not know. We also invited respondents to explain their answers in a free-text box. 286 respondents gave free-text answers.

75% of those responses emphasised that people who had already been assessed by an IBSS should not need further assessment by IBCA to show their eligibility and that there was no reason to expect someone to go through the same assessment process twice.

Some respondents felt that the proposal did not go far enough and gave suggestions for how it could be changed. 7% suggested that the award should be automatically paid to all infected people without the need for any assessment, 5% expressed concern that the award would not provide more compensation for people infected with HIV, and 3% felt that the uplifts through the award were too small. A few respondents felt that people assessed by an IBSS should not be automatically eligible because assessments made by the IBSS were inconsistent or were not sufficiently rigorous.

Question two *asked whether respondents agreed that other people, not registered with an Infected Blood Support Scheme, should be able to apply for such an award.* In doing so, they would be assessed against the criteria used by the England Infected Blood Support Scheme (EIBSS).

437 respondents chose to answer this question. Of these respondents, 347 (79%) said they agreed with the proposal. 27 (6%) said they disagreed with the proposal. 63 respondents (14%) said they did not know. We also invited respondents to explain their answers in a free-text box. 247 free-text responses were given to this question.

74% of responses emphasised that this was a necessary step to ensure that those people who had never been assessed by an IBSS would be able to receive this award. It was seen as particularly important for those people who were not eligible for an IBSS, such as people infected with Hepatitis B or those infected with Hepatitis C after the cut-off date for IBSS eligibility.

5% of respondents said that there should be no assessment process at all, and that anyone who applies for the award should receive it automatically.

4% of respondents specifically said that it was appropriate to use the EIBSS criteria because they were the criteria which most IBSS recipients had been assessed against, while a slightly smaller number of respondents indicated that they would prefer the criteria of a different IBSS scheme to be used.

Question three *asked whether respondents agreed with the proposed adjustment to the level of the Financial Loss award for people eligible for this award.*

305 respondents chose to answer this free-text question. 50% of respondents agreed that the proposed adjustment to the Financial Loss award was proportional to the effect on day-to-day life they would expect someone eligible for SCM to experience.

28% of respondents felt that the adjustment was insufficient, though they provided different reasons for this. 3% of respondents indicated the award was insufficient but did not give an alternative number they felt was appropriate. Others suggested that the adjustment should be higher, and suggested figures. These ranged in size. 4% of respondents suggested that people eligible for the award should receive financial loss compensation on the basis of 80% financial loss (i.e. equivalent to the amount of financial loss compensation paid to people with Hepatitis B or C and cirrhosis of the liver). 13% suggested that people eligible for the award should receive financial loss compensation on the basis of 100% financial loss (i.e. equivalent to someone diagnosed with HIV, or someone with Hepatitis B or C and decompensated cirrhosis or liver cancer).

13% of respondents said that IBCA should be able to assess individual cases and calculate Financial Loss awards on a case by case basis, with some people saying the proposal should act as an automatic “floor” and that people could receive more than that if individually assessed.

Question four *asked whether respondents agreed with the proposed adjustment to the level of the Care award for people eligible for this award.*

425 respondents chose to answer this question. Of these respondents, 175 (41%) said they agreed with the proposal. 130 (31%) said they disagreed with the proposal. 120 respondents

(28%) said they did not know. We also invited respondents to explain their answer in a free-text box. 238 free-text responses were given.

26% of these responses agreed that the proposal offered a fair amount of compensation for the care needs of someone eligible for SCM.

About half of free-text responses felt the award was insufficient to recognise the care needs of someone eligible for SCM. Of respondents who felt the award was insufficient, 70% said they felt the amount was insufficient but did not specify what they thought a better amount would be. Where specific figures were suggested these ranged from seven hours a week (i.e. one hour a week more than proposed) to 24 hours per day care (i.e. 168 hours per week, 162 hours more than proposed).

Some respondents who felt the amount proposed was insufficient also used the free-text box to explain what type of care they thought people eligible for SCM needed. 41% of respondents did not specify the nature of the further care needed. 37% mentioned needing additional care for domestic duties (such as cooking and cleaning), 25% for the provision of emotional support, 23% for attending medical appointments and 17% for support with personal hygiene. Other reasons given included: helping people with medication, mobility, personal administrative tasks (such as managing household bills), general support due to poor physical health.

A small number of responses indicated the need for end-of-life care, for overnight support, childcare, or to account for the travel time of the person providing care (for example, to travel to the infected person’s home).

24% of respondents said that the amount of compensation given should be determined through individual assessment of each claimant’s care needs.

Whilst we did not ask a specific question about these points, some respondents said they were concerned about what the proposal meant for claims on behalf of deceased infected people, and how start dates for the award would be determined.

A smaller number of responses criticised the proposed start dates. These responses often suggested that the award should date from when the condition that made someone eligible for SCM was “diagnosed” or when someone was treated with interferon. These responses tended to note that SCM was only made available from 2017 and that some people’s symptoms started before this date. Other respondents challenged the proposal that the award is only available for those not registered with an IBSS from 2024, suggesting it is unfair that they are disadvantaged because they were not eligible for an IBSS and that the eligibility criteria for the IBSS should have been wider.

Government response to the consultation

How the compensation scheme will change
We will create a new supplementary route award for people who were, or would have been, eligible for SCM. People eligible for this new award will receive more financial loss and care compensation.

People who were assessed as eligible for SCM by an IBSS scheme will be automatically eligible for this award and will not need to go through any further assessment process to receive it. Other infected people will be able to apply for the award, and will be assessed against the criteria previously used by EIBSS.

People eligible for the new award will receive uplifts to their Financial Loss and Care awards from 2017, which is when SCM was first introduced.

Eligibility for the new award
The consultation responses clearly supported the proposal to make the award automatically available to those who were assessed by an IBSS. They also showed support for other people being able to apply for this award.

We will therefore make the necessary changes to the regulations to implement those proposals.

The consultation responses did show that some people were concerned that - apart from those who were assessed by an IBSS scheme whilst they were still alive - this award would not be available to estates.

In the consultation, we explained that this is because we think it is very unlikely that an estate would be able to be properly assessed by the criteria used by the IBSS. The assessment criteria used were about how the person's condition impacted their ability to discharge their daily duties and would continue to in future. This is because the SCM and equivalent payments were designed to make sure people got the right support with their ongoing, day-to-day life. The assessment process included testimony from the applicant themselves.

In the case of an estate claim, there would be no way to take testimony from the infected person directly. Further, the intention of SCM was to account for someone's ongoing needs, which are not assessable for an estate claim.

This is different from those cases covered by the existing Severe Health Condition route, which rests on a medical diagnosis of specific conditions. In those cases, an estate **is** able to apply for a supplementary award. This is because they will be able to use medical records as proof of their diagnosis with a specific condition. Where these criteria are met, the claimant receives the same uplift as someone eligible for the award discussed above.

We will therefore not be opening this route up to estates, except where the claim is being brought by the estate of someone who was previously assessed as eligible for SCM (or its equivalents) by an IBSS.

The date from which the new award will be paid

The consultation responses also showed concern about the proposal for the award to be available from the date of assessment for those who were assessed by an IBSS and from 2024 for those who were not.

IBSS assessments were not designed to look back at someone's past experiences or to determine the first point at which someone would become eligible for the award.

Responses that were concerned about this aspect of the proposal often suggested that the award should date from when the condition that made someone eligible for SCM was diagnosed. However, the criteria that makes someone eligible for SCM or an equivalent does not always come with an exact diagnosis date or specific clinical 'marker' that could be used to determine a tailored start date for each person. For example, if a person suffers from a particularly high level of fatigue that makes it very challenging for them to engage in day-to-day activities, they would not typically have a specific start date for the onset of their fatigue in medical records.

As such, we do not believe it would be feasible to determine a specific eligibility date for each claimant.

However, responses also noted that the SCM and its equivalents were introduced in different parts of the UK at different times, so some people did not have the opportunity to be assessed until later than others. Responses also noted that not everyone eligible for compensation from IBCA was eligible for IBSS (notably, people infected with Hepatitis B and people infected with Hepatitis C after a particular date). Respondents felt it was unfair that some people would receive less compensation than others because of this, simply because of where they lived or whether they were eligible for IBSS.

We agree with these concerns and recognise that our original proposal should be changed to help address them. We will therefore backdate the award for all eligible people to 2017.

People who were assessed by an IBSS, will have their Financial Loss and Care awards adjusted from 2017, even if they were assessed at a later date. People who were not assessed by an IBSS will have their Financial Loss and Care awards adjusted from the same date.

This will mean up to an extra seven years of compensation for claimants. We believe this change will also reduce inequity between people eligible for this new award. It will avoid disadvantaging people who were not able to apply for this award until a later date, whether this is because SCM-equivalent awards became available later for the scheme they were registered on, because there was a delay in them being assessed or because they were not eligible to be registered on an IBSS scheme.

Amount of Care and Financial Loss compensation

Responses were generally supportive of the proposals we made for the amount of financial loss and care compensation that people eligible for this award will receive. The proposal means that someone eligible for this award would get more financial loss compensation than someone with chronic Hepatitis, but less than someone with cirrhosis of the liver. It also means that they would receive an annual Care award for domestic support and ad hoc care. As set out above, respondents who did not support the proposals provided different views on what they felt would be an appropriate award while others suggested individual assessment would be the best way to calculate financial losses.

As noted above, some respondents indicated specific award levels that they felt were appropriate, but those levels varied dramatically making it hard to identify a specific level that most respondents would agree with.

Having considered the responses to the consultation (which were broadly supportive) and taken the advice of the TEG, we will implement the levels of compensation set out in the consultation.

Overall, this means that people who were assessed as eligible for SCM (or its equivalents) by an IBSS and people who in future go through a similar assessment by IBCA will be eligible for a Severe Health Condition award. This will be part of the Scheme's supplementary route. Those who were assessed by an IBSS will be automatically eligible, while those who were not will be assessed for eligibility.

For people eligible, Financial Loss and Care awards will be adjusted from 2017 to the point of their healthy life expectancy. Their Financial Loss awards will be adjusted, using an assumption that they retained only a 30% ability to work (40% if they were likely to have benefited from effective treatment) and they will be assumed to have care needs amounting to ad hoc care and domestic support.

This would mean an annual Financial Loss award of £20,760 (or £17,794) and a Care award of £5,460 for each year of eligibility (unless the person was already entitled to an award at the same level or higher).

Section 2: Severe Psychological Harm

Inquiry recommendation: *"The approach of the Infected Blood Psychology Service is adopted so that both a diagnosis made by a psychiatric professional and a formulation-based opinion of all qualified psychological and counselling professionals are accepted as sufficient evidence of severe psychological harm and that such evidence should qualify a person for a supplementary Severe Health Condition award without the additional need to demonstrate a period of consultant-led secondary mental health treatment or assessment/treatment as an inpatient."*

Summary of the consultation responses

The first question asked: *The majority of victims of the infected blood scandal have suffered psychological harm. The Scheme compensates for this in three ways, depending on the severity of harm suffered:*

- *Core route*
- *New proposed Severe Health Condition award for SCM*
- *Severe Health Condition award for severe psychiatric disorders*

Across these three different awards, are the mental health effects of infection or treatment fully covered by the compensation offered? If you answered no, what other mental health issues do you think the Scheme should consider?

This was a multiple-choice question inviting people to say if they agreed, disagreed, or did not know whether the proposal covered mental health effects from infection/treatment.

We received 406 responses to this question. Of these, 99 (24%) respondents said 'Yes', agreeing that the range of mental health issues experienced by infected people were taken into account by the proposal. 215 (53%) said 'No', they thought that the mental health effects of infection and treatment were not fully covered by the proposal. 92 (23%) said they did not know whether the proposal fully covered the mental health effects of infection and treatment.

We received 273 free-text responses to this question. We asked people to provide more information in the free-text box specifically if they felt the proposal did not fully cover the mental health effects of infection and treatment. The responses given covered a range of different issues and themes, which we have summarised here.

64% of respondents used the free-text option to set out a broad range of mental health issues, conditions and disorders experienced as a result of infected blood. The most common mental health issues that people said should be covered were: the mental health impact on affected people (7% of responses); Post-Traumatic Stress Disorder (PTSD) (7%); depression (7%); stigma due to infection (6%); and anxiety (5%). A few people said they thought interferon treatment that caused psychological harm should be covered (5%). A further few said bereavement, grief and loss, and suicide/suicidal ideation/suicidal thoughts should be compensated by the Scheme (4%). Finally, a few responses mentioned other, unspecified mental health issues (3%).

18% of responses were critical of the proposed award amounts and the overall design of the Scheme. A few respondents told us that people did not seek psychological help for their mental health issues (6%), or that some people were not offered or had no access to mental health support (5%). A few said the evidence criteria for the Severe Health Condition award for Severe Psychiatric Disorders was too high (3%).

8% of responses explained how mental health issues had affected daily lives and life choices, and provided examples including: a reduced ability to work; inability to form relationships/relationship breakdown; and physical health issues caused by mental health issues (e.g high blood pressure).

5% of responses gave alternative proposals for the design of the Scheme, the most common of these being that a basic core route award for psychological harm should be introduced, and be available to all infected people (2%).

The remaining 5% responses either said that they agreed with the proposal; gave no relevant answer; commented on the consultation being too long and/or confusing; or said they did not know.

The second question asked *To qualify for the Severe Health Condition award for severe psychiatric disorders, infected people must currently provide a report from a consultant psychiatrist confirming a diagnosis and causation, alongside evidence of extensive treatment (a six-month period of consultant-led secondary care, inpatient admission, or section under the Mental Health Act).*

What other pre-existing evidence could the Scheme ask applicants to provide to demonstrate severe psychological harm, similar to the Severe Health Condition award for Severe Psychiatric Disorders?

256 people responded to this question. 52% of responses provided sources of medical and clinical evidence they thought could be used to demonstrate that someone experienced severe psychological harm. The most common suggestions were: GP records (8%); general medical records (8%); and prescriptions for antidepressants (6%).

19% of responses said evidence could be provided from non-clinical sources, including: witness statements or personal testimony (8%); and evidence of the impact on ability to work (such as employer/occupational health/benefits statements) (6%).

16% of responses discussed the barriers to evidence people face when applying for the Severe Health Condition award for Severe Psychiatric Conditions. The most common of these was a lack of evidence due to not seeking or having access to psychological help (12%).

7% of responses suggested alternative ways that people could qualify for the Severe Health Condition award. The most common suggestion was that no further evidence should be needed or that every infected person should automatically qualify for the Severe Health Condition award for Severe Psychiatric Conditions (4%).

The remaining 6% of responses provided the following feedback: they said they did not know; they told us that interferon treatment caused psychological harm; or gave no relevant answer.

Government response to the consultation

How the compensation scheme will change

For some people, the amount of financial loss and care compensation available as part of their core compensation award is not sufficient to reflect the impact that poor mental health had on their care needs or ability to work. The new Severe Health Condition award for SCM will ensure the Scheme fully recognises the impact of severe psychological harm by giving people in this situation more financial loss and care compensation.

This change will mean that the core route awards, the new Severe Health Condition award for SCM, and the existing Severe Health Condition award for Severe Psychiatric Conditions all offer compensation for the range of mental health issues that infected people have suffered.

The Scheme is designed to recognise that most victims of the infected blood scandal have suffered some form of psychological harm as a result of what happened to them. That is why the core route Injury award has been calculated at a rate that compensates everyone for this type of harm. However, it is clear from the responses that, amongst other issues, the way the core route recognises this harm has not been explained clearly enough. This has led people to be uncertain about whether their circumstances, or those of their loved ones, are being properly addressed as part of their compensation offer.

We looked at all the mental health issues people said should be covered by the Scheme. We wanted to see if these were already part of our proposal or if more change was needed. To help us, we asked experts from the TEG to review the responses. This group includes experts who specialise in mental health (a psychiatrist and two psychologists).

We asked the TEG to look at all the mental health issues people said the Scheme should cover in the consultation. The TEG reviewed these in full, and advised us that the new SCM award is a better way to recognise severe psychological harm. Instead of focusing on a specific medical label or diagnosis, the SCM award looks at how much the harm affects a person's life, such as their ability to work or look after themselves. The TEG told us that each of the mental health issues in the consultation vary greatly in severity from person to person. The TEG confirmed that this SCM award can therefore cover the wide range of mental health issues mentioned in the consultation, such as PTSD, depression, and anxiety, if they are severe enough to impact daily life.

We also considered the different types of evidence that respondents suggested could be considered as part of someone's application for the existing Severe Psychiatric Conditions Severe Health Condition award. We provided the TEG with all types of evidence given in the consultation responses and asked them to look at the three specific areas that were most commonly mentioned in the responses to see if anything could be done in response to them.

Prescriptions: People suggested using records of antidepressants as proof of psychological harm. The TEG advised against this because these medicines are used for many different reasons and do not always show how severe someone's condition is.

Historic suicide: We recognise that anyone who has died by suicide, or attempted to die by suicide, as a result of what happened to them, will have been suffering from profound mental anguish. We therefore asked the TEG to look at whether records of suicide from before 21 May 2024 (the date the Scheme was announced) could be used as evidence for the award. The TEG advised that the Scheme cannot require applicants to prove that an infection was the specific cause of a someone's suicide. They felt it would be a retraumatising ask of loved ones applying to the Scheme on behalf of the infected person's estate. While we could try to limit this to suicides that happened before the Scheme was announced, we are concerned that this distinction could easily be misunderstood and put a vulnerable person at risk today. Even with the best explanation, we believe that linking more compensation to evidence of suicide creates a risk that the Scheme is misinterpreted, and places vulnerable people at risk if they feel pressured to harm themselves to help their families get more compensation.

Treatment by psychologists: We asked the TEG to look again at whether treatment by psychologists, or certain types of psychologist, could be used as evidence for the award. The TEG highlighted that not everyone has had the same access to psychology professionals, and that they heard this clearly from their own roundtables. They noted that an approach relying on this kind of professional opinion could make the award more unfair. We think that the new SCM Severe Health Condition award captures the types of things people might have seen a psychologist for, such as the mental health issues raised in the consultation.

We have therefore concluded that the new SCM award provides the fairest approach to broadening the criteria to recognise psychological harm from the infected blood scandal, and therefore the best way to give people more appropriate compensation for the harm they experienced.

It provides people with a Financial Loss award of £17,794 (post-effective treatment) or £20,760 (before effective treatment) per year until retirement age (66 years); and a Care award of £5,460 per year to cover weekly domestic and ad hoc care for life. The Severe Health Condition award for Severe Psychiatric Conditions exists to still compensate for the most severe harm at 100% financial loss.

This means the Scheme will now offer three levels of support for mental health:
- The core route: for the general mental injury, distress, and stigma that almost everyone has suffered.
- The new SCM award: for people whose poor mental health as a result of their infection or treatment has had a major impact on their ability to work and live their daily lives, meaning they suffered more financial loss and required more care than the core route compensation has given them
- The Severe Health Condition award for Severe Psychiatric Conditions: This will stay in place for those who have a diagnosis of a severe psychiatric disorder and have had specialist hospital care, leading to total inability to carry on working.

Section 3: Recognition of Harm caused by Treatment with Interferon

Inquiry recommendation: *"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".

Summary of consultation responses

Question one asked, *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?* This was a multiple-choice question inviting people to say 'Yes', 'No' or 'Don't know'.

We received 440 responses to **Question one**. Of those, 245 responses (56%) said 'Yes' they did think there were short-term side effects that we had not taken into account in the Level 2B proposal, while 65 responses (15%) said 'No', suggesting these respondents believed that all short-term side effects were covered by the proposal. 130 respondents (30%) said they did not know, suggesting they were unsure whether the proposal accounted for all short-term side effects of interferon treatment or not.

Question two was a follow-up to the first question and asked *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*. This question was a free-text question. It allowed people to describe the short-term side effects of interferon treatment that they believed had not been reflected in the Level 2B proposal, and to explain how those side effects impacted the amount of care a person needed or their ability to work within the two years of commencing interferon treatment.

247 respondents chose to give more detail in their free-text answers to **Question two**. In these responses, people described a broad range of both physical and psychological side effects. The most common physical side effects that people said they had experienced included: fatigue (20% of responses); flu-like symptoms (11%); difficulties sleeping (11%); and nausea (11%). Other physical side effects that many people reported included: weight loss (10%); joint and muscle pain (10%); skin issues (9%); hair loss (9%); weakness (7%); and anaemia (7%). The most common psychological and cognitive side effects that people described were depression and low mood (26%); mood changes including anger (18%); and anxiety (16%). Some people also said that they had suffered with brain fog or concentration problems (16%), suicidal thoughts (14%) and memory loss (9%).

Some people used their response to tell us more about the impact that these short-term side effects had on their lives, saying that they were less able to work/study (25%) and carry out day-to-day activities (15%). Other people said that, due to side effects of interferon, they experienced difficulties in relationships (13%), struggled with psychological trauma (9%) and were more socially withdrawn during and shortly after treatment (6%). A few people told us that they were not able to work at all for periods of time within the two years after interferon treatment due to side effects, and that at times they needed 24/7 care from loved ones (2%).

Question three asked, *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? As a reminder, the Severe Health Condition award currently gives compensation for people who have autoimmune diseases triggered or made worse by interferon and severe psychiatric disorders. The new proposal gives more compensation to people who meet the criteria set out by the IBSS 'Special Category Mechanism' or equivalent.* Again, this was a multiple-choice question, asking people to select ‘Yes’, ‘No’ or ‘Don’t know’.

We received 430 responses to **Question three.** Of those, 295 respondents (69%) said ‘Yes’ they did think there were long-term side effects of interferon treatment which lasted more than two years and were not covered by the proposed Severe Health Condition award. 29 respondents (7%) said ‘No’ suggesting they thought long-term side effects had been covered by the Severe Health Condition award. 106 respondents (25%) said they were unsure whether the Severe Health Condition award had accounted for all long-term side effects or not.

Question four asked *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.* Again, this was a free-text question which encouraged people to tell us about any side effects of interferon treatment that lasted longer than two years and were not already covered by the Severe Health Condition award. The question also encouraged people to tell us what those long-term side effects meant for the amount of care a person might need and how they impacted their ability to work.

275 respondents chose to give more detail in their free-text answers to **Question four.** Many people described physical and psychological side effects lasting longer than two years that either they or their loved ones had experienced. The most common physical side effects that people described were: fatigue (31%); skin issues (13%) and sleep problems (12%). Other people said they had experienced: long-term joint and muscle pain/swelling (11%); thyroid problems (10%); autoimmune disorders (7%); and nerve damage (6%). The most common psychological or cognitive side effects that people described experiencing were depression and low mood (27%); and difficulty concentrating (23%). Some people described more generalised mental health impacts (22%). Some people also said that following interferon treatment, they had struggled with: anxiety (15%); memory loss (11%); trauma (11%); changes in personality or behaviour (9%); and mood changes (8%).

Some people told us that long-term side effects following interferon treatment had affected their ability to work (20%), or form or maintain relationships (12%). A few said they experienced a general reduction in their quality of life (8%). Very few responses quantified the extent to which their earning capacity or care needs were affected by the long-term side effects of interferon treatment they had suffered.

A few people provided alternative proposals to the one in the consultation. One suggestion was that people should get an automatic uplift to Level 3 if they received interferon (5% of responses); another was that there should be an uplift for each round of interferon treatment (2%). A few people also provided general feedback on our proposal. This included a few people saying that the long-term impacts of interferon cannot be quantified (2%).

Government response to the consultation

How the compensation scheme will change
People who were treated with interferon will receive more compensation for the impact the treatment had on their life. To do this, we will create a new Level 2B infection severity band to give eligible people higher Injury, Financial Loss and Care awards than they receive at Level 2.

People who were treated with interferon more than once will now also receive additional financial loss and care compensation for each additional round of treatment.

It is clear from the consultation that lots of people who were treated with interferon struggled with a broad range of side effects. We acknowledge that people's experiences were deeply personal and that in some cases, the impact of interferon treatment has continued even after treatment ended. We recognise that some people suffered such debilitating side effects that they had to stop treatment after a short period. **For that reason, anyone who can show they have received interferon treatment will automatically qualify for the Level 2B award**. There will be no minimum treatment period to qualify for the Level 2B award, and everyone treated with interferon will be eligible even if they were only able to tolerate the treatment for a number of weeks.

We have carefully reviewed all the side effects that people said they experienced. In doing so, we were looking to understand whether there were any side effects that we had not previously taken into account when we designed the proposed Level 2B severity band. Where this was the case, we considered whether we needed to make any changes to the award levels to better reflect the experience of most people treated with interferon. To help us with this, we asked clinical and legal experts from the TEG to review the consultation responses and to consider whether any changes were needed to their previous advice on how the scheme could recognise the harm caused by interferon treatment.

Based on the responses to the consultation and clinical expertise, the TEG advised that the Level 2B proposal does appropriately compensate people for the financial loss and care requirements they would have required due to the short-term side effects that most people suffered as a result of interferon treatment.

The TEG acknowledged from the consultation and its own engagement with the community, that some people have experienced side effects following interferon treatment that continued beyond two years. In some cases, it is clear these side effects have had a significant impact on people's lives. The TEG concluded, however, that on balance, it could not say that most people who received interferon treatment were likely to suffer side effects lasting beyond two years. As the Scheme is based around tariffs, it is important that the levels of award reflect the experience of most people. On this basis, the TEG advised that the Level 2B proposal appropriately recognises the negative effects that most people suffered and no further changes are needed. The TEG advised that in cases where people have suffered symptoms for more than two years that prevented them from working, they would be eligible for a Severe Health Condition award on the basis of long-term disability. This would mean that the person received compensation based on the long-term disabling impact of the conditions they experienced, rather than the interferon treatment itself, but that they would nevertheless be able to apply for compensation for what they suffered.

We know that a few people who responded to the consultation feel very strongly that everyone who had interferon treatment should be uplifted to Level 3. The evidence provided in the consultation paints a vivid picture of how devastating interferon treatment could be for some people. We recognise that for some people, the damage from interferon has been lasting and severe. Whilst we have given this serious consideration, we think that Level 2B appropriately recognises the negative effects that the majority of people treated with interferon suffered. This approach allows us to give everyone who had interferon treatment appropriate recognition, while still providing a way for those with the most severe long-term impacts to have their individual circumstances recognised through the Severe Health Condition award.

The TEG has recommended a further change to the Level 2B proposal as a result of the consultation. This is so that it better compensates people who received interferon treatment more than once. People who received interferon treatment more than once are likely to have suffered side effects during each round of treatment, meaning they had multiple periods in their life where they needed higher levels of care and their ability to work was affected. We accept the TEG's advice and will make changes to the Scheme to give additional Care and Financial Loss awards, at the same level as the Level 2B proposal, where people have been through more than one round of interferon treatment, at least two years apart.

The TEG advised that in some exceptional cases, people may have had two separate rounds of interferon treatment in the same two-year period. In this circumstance, they would be given an additional Care award at the same level as Level 2B (one year low-level care), and one additional year of financial loss at the same level as Level 2B (80% reduction in earning capacity).

A summary of the new Level 2B infection severity band and what it means for eligible people's compensation is below:

Eligibility	**Anyone who can evidence treatment with interferon** (with or without other drugs, such as ribavirin) will automatically qualify for Level 2B, without having to prove the duration of their treatment, side effects, financial loss or care needs.
Injury award	Anyone eligible will receive a **£10,000 uplift** on the current Level 2 band, bringing the total value of the Injury award to £70,000.

Financial Loss award	Anyone eligible will receive a **two year uplift of financial loss to 80%** (compared to 40% at Level 2). The total award value would therefore be £23,726 per annum (80% of UK median salary plus 5%) for two years (the year in which interferon treatment was started and the year after) before reverting to the Level 2 level.
Care award	Anyone eligible will receive one additional year of low-level care (16.5 hours per week, for the year) compared to Level 2.

People who received multiple rounds of interferon treatment will be eligible for additional Financial Loss and Care awards, as set out above. All Care awards will be discounted by 25% in line with wider scheme policy on past care, unless a person can show that they paid for professional care.

Section 4: Past Financial Loss and Past Care Awards

Inquiry recommendation: *"'x' be removed from the equation set out in Regulation 7."*

Summary of consultation responses

Past Care

385 respondents chose to answer question one on past Care, which asked whether respondents felt it was fairer to remove the 25% deduction to past Care (which is what the Inquiry recommended), or to instead include the deduction in the calculation to determine whether an additional award is paid to someone's estate when they die. Of these respondents, 146 (38%) indicated they were in favour of the first option. 49 (13%) indicated they felt the alternative option was fairer. 190 respondents (49%) said they did not know.

Amongst respondents who did express a firm view, 75% of respondents indicated they were in favour of the first option, and 25% indicated they were in favour of the alternative option. This indicates a clear preference for option one. However, the answers overall show a high level of uncertainty, with almost half of respondents stating they did not know which option to support.

Past Financial Loss

392 respondents chose to answer question two on past financial loss, which asked whether responses were in favour of the current calculation (i.e. averaging the calculation for past financial loss) or changing the calculation so that a strict-year-on-year approach was used, with no averaging. Of these, 95 (24%) indicated they were in favour of the current calculation. 100 (26%) indicated they felt that a year-by-year calculation that did not average the award was fairer. 197 (50%) did not know which was fairest, or had no opinion.

Discounting respondents who did not know or had no opinion, 49% of respondents preferred averaging whilst 51% preferred using a year-by-year value. The answers also overall show a high level of uncertainty about the options. Half of the respondents stated they either did not know which answer was fairest, or had no opinion on it.

Of the 392 respondents who answered question two, 205 provided more information to explain their response in the free-text box. Some respondents used the free-text box to reaffirm which option they felt was fairest, and some used it to explain in more detail why they had chosen a particular option. Other respondents explained that they did not know which was fairest and in some cases explained why they felt that way. A few respondents suggested an alternative way of looking at past Financial Loss that they felt would be fairer than choosing one of the two options we set out. Finally, some respondents provided details not directly relevant to the question.

Where respondents did use the free-text option to give a reason why they felt their chosen option was fairer, we identified the following themes:

Responses in support of option one (averaging)

Some respondents who preferred averaging explained that this was because it was important that the calculation did not disadvantage people infected as children. A few respondents felt that keeping the averaging approach would make the Scheme easier for IBCA to administer.

Responses in support of option two (non-averaging)
Some respondents felt the year-by-year calculation was a more accurate way to look at someone's past Financial Loss and compensate them for it. A few respondents felt that the year-by-year calculation was a better reflection of the Inquiry's view on what should change.

Other responses
A few respondents felt that another, alternative, option would be fairest. These responses generally gave one of two suggestions:

- To run the calculation both ways and give claimants the choice of which option they would prefer
- To run the calculation both ways, and determine claimants' awards on the basis of whichever calculation is most beneficial to them.

Respondents who did not know which option was fairest
Most respondents who said they did not know which answer was fairest or had no opinion explained that this was because the proposals set out were, in general, too complicated to understand. Some respondents explained that they did not understand enough about how the proposals affected their or their loved one's specific circumstances to give an informed view on which they felt was fairest.

Government response to the consultation

How the compensation scheme will change
The 25% deduction applied to past care for people who choose to continue receiving support scheme payments will be removed, meaning they receive more compensation to recognise the care they have received.

Rather than choosing one of the two options IBCA will instead use both ways of calculating past Financial Loss. This means whichever option gives a claimant a higher value award will be used to calculate their compensation.

The most common response to both questions was that respondents did not know or did not have an opinion on the options set out. We acknowledge that the recommendation, the proposals, and the equation that they affect are not straightforward to understand. We also recognise that for many respondents, the effect that the proposals would have on their own award, or their loved one's award, may be difficult to judge. We hope that the case studies provided in the consultation document, alongside the short video explanation of the proposals available on GOV.UK, helped some respondents feel more confident in choosing an option.

In the 'Implementing the Changes: What Happens Next?' section of this document, we set out what we are doing to help people better understand the Scheme and what the results of this consultation mean for them.

To determine the response to the specific questions in this section, we have also considered what the Inquiry recommended and why. That is because the Inquiry's recommendations came directly from engagement with the infected blood community. We have also taken into account which options are likely to have an impact on the ongoing delivery of compensation to victims.

Past Care

The consultation showed support from respondents for the Inquiry's recommendation to remove the 25% deduction to past care for people who choose to receive support scheme payments for life. **We agree that a change should therefore be made to the relevant calculation.**

This change means that, for people who choose to take support scheme payments for life, all care, regardless of whether it happened in the past or not, will now be given the same value for the purposes of calculating their compensation.

This change will affect people who have already claimed compensation from IBCA, and some people who have not yet claimed. This means that some people's claims will need to be reviewed. We expect that where someone has already accepted their compensation award and is therefore owed additional compensation as a result of this change, IBCA will review their claim and let them know how much more compensation they will receive. We do not expect that claimants will need to do anything as part of this process.

Past Financial Loss

Responses did not show clear support either way for keeping the calculation for past Financial Loss the same as it works now, or changing it. The specific recommendation that the Inquiry made would not affect people's Financial Loss awards.

Unlike the change to the calculation for past care, not every relevant infected person's compensation would go up as a result of a change to the calculation for past Financial Loss. Some people would get less compensation than they would expect to get now. How people's compensation awards would be affected by the change is down to their personal circumstances but, as the consultation explained, it is likely that people infected in childhood will receive less compensation than they do now if the calculation changes. Keeping the calculation the same as it works now or changing it would mean that some people's expected awards would reduce in size. We recognise that this would therefore be a change that directly advantages some people, and disadvantages others.

We are grateful to those respondents who took the time to suggest alternative options that they felt would be most fair to most claimants. We have considered these in detail. Running both calculations and giving each individual claimant whichever is the highest amount in their personal circumstances would mean no one was disadvantaged by the way we calculate past Financial Loss. **We will make sure that people receive past Financial Loss compensation based on whichever of the two calculations is most financially beneficial for them.**

Section 5: Evidence Requirements for Exceptional Loss

Inquiry recommendation: *"The Cabinet Office consult on whether the evidential requirements for exceptional reduced earnings are likely to prove a barrier to people who have sufficient evidence that their eligibility for such an award could with confidence be established on a balance of probabilities, and if so to consider what if any provision might be introduced to enable them to access an award."*

The Inquiry also commented on the situation of people who were infected early in life or in working life before they had been able to realise their potential. It acknowledged that in the case of a child *'it is unusual for there to be any evidence which will show on balance of probabilities that earnings would be any higher – or any less – than median earnings'*. However, it suggested that there could be cases where the evidence is strong that the potential for higher than average earnings was real, and gives the case of someone who has started professional training with every apparent prospect of succeeding but is then infected and therefore unable to pursue their career.

Summary of consultation responses

The responses we received to the questions about this topic were broad and sometimes very wide-ranging. For this reason, in this section we explain what key themes we identified from responses rather than the percentages of respondents who raised a specific topic.

Question one asked: *In cases where someone believes their earnings would have exceeded the salary assumptions of the core route (UK median salary + 5%) had they not been infected, but cannot prove this from salary and other records, are there forms of evidence (e.g., professional qualifications) that IBCA could consider when calculating an Exceptional Loss award?* This was a free-text question asking people to think about cases where a person has never earned above the core route but thinks they would have done so if they had not been infected, and what IBCA could use to calculate awards in these cases.

We received 202 responses to **Question one**. Respondents made a wide range of suggestions about the types of evidence IBCA could consider in cases where people never earned more than the core route, but would have been likely to if they had not been infected.

Many responses suggested IBCA could use a form of professional benchmarking, for example, looking at a person's professional or academic qualifications and using that information to predict how much a person would have earned in a particular profession and location. Other people suggested that IBCA could look at how much a person's peer group or family members earned and use that to predict what a person may have earned. Some people suggested that IBCA follow a similar approach to what a court may do, by assessing each person's individual situation (e.g. family background, education) and taking statements from other people (e.g. family members or teachers) to decide whether that person should be eligible for an Exceptional Loss award. Alternatively, a few people suggested that a new flat-rate Exceptional Loss award could be introduced for people who never worked in a high-paying job, but who on a balance of probabilities were likely to do so.

Question two asked: *If changes were made to bring more people within the scope of the award, how could the Scheme ensure that there is fairness in treatment for people who cannot provide the additional evidence listed in question one (for example if they did not belong to a profession with training and qualifications)?* This was a free-text question which asked people how IBCA could make sure the award was fair if it were to open to people who had no proof of earnings.

We received 168 responses to **Question two**, which was about how we could make sure the Scheme is fair if we allow people without evidence of higher earnings to access awards for Exceptional Loss.

The responses to this question suggested people have conflicting views on this topic. While some people suggested that IBCA could use a person's professional and/or educational achievements and compare these to the average career salaries of a given profession, other people suggested that limiting the award to people with professional and academic achievements would disadvantage people on career paths that did not need formal qualifications. Other people who were not supportive of opening the award to people without evidence said that people's past educational attainment could not be taken as a guarantee that they would have earned more in future. Responses also highlighted conflicting views about whether witness statements and testimonial evidence would make the award fair, with some people supportive of this approach and others suggesting that the award could only be fair if everyone was asked to provide documentary evidence.

A separate group of responses suggested that we could achieve fairness by standardising the awards for Exceptional Loss, for example by introducing a maximum cap or by giving flat-rate awards to different cohorts (some cohorts suggested included: children; people with university degrees; and people with certain levels of evidence). Finally, some people suggested ways that IBCA could help to achieve fairness in the way it delivers the award, for example by publishing clear criteria for the awards or introducing a moderation panel to review claims to improve consistency.

Finally, **Question three** asked: *What types of evidence could IBCA take into account when someone says they earned beyond what is provided for under the core route but no longer has documentary evidence to prove so?* This was a free-text question which asked people to think about cases where a person does not have documents to prove their past earnings, and what IBCA could use to calculate awards in such cases.

We received 165 responses to **Question three.** It was clear from the responses that most people thought IBCA should accept a broad range of evidence of a person's past earnings given that many people are unlikely to have historic payslips. The most common suggestion was for IBCA to accept other types of financial records such as bank statements, tax records, pensions records and accountant/business records. Many people also suggested that IBCA should accept records of someone's employment (for example work contracts or records of attending professional events) as proof that they were working in a certain job. Another theme of responses, as in previous questions in this section, was for IBCA to use professional benchmarking, which might involve comparing a person's professional and educational achievements with average career earnings of a specific profession or location, or comparing to earnings of former colleagues. Many people thought that IBCA should be able to use testimonial evidence to verify a person’s past earnings, while some other people said IBCA should be able to use their discretion to judge whether a person should receive an Exceptional Loss award or not. Finally, some people did not agree that people should be able to access the Exceptional Loss award without documentary evidence, with some concerns raised about fairness and the risk of fraud.

Government response to the consultation

How the compensation scheme will change
More compensation will be available for people who would have had the potential to earn higher than average if it weren’t for the impact of the infection on their life, but who do not have actual evidence of higher earnings. We will introduce a new £60,000 award for infected people who can show that they had entered or had an offer to enter a career where the median gross salary is 10% higher than the gross median earnings in 2023, but who were unable to progress this career due to their infection.

We will work with IBCA to make sure that people who are eligible for the Exceptional Loss award are able to access it when IBCA opens the supplementary route. We will make sure that IBCA takes into account a wide range of evidence of actual earnings as part of someone’s application for this award.

We understand the concern that missing payslips might prevent eligible people from receiving an Exceptional Loss award, and that people may be anxious that a lack of comprehensive historic records may prevent them from receiving an award they should be entitled to. We can confirm that payslips will not be the only form of evidence that IBCA accepts. The regulations underpinning the Exceptional Loss award do not limit the types of evidence that IBCA is able to accept. This is so that the regulations do not inadvertently prevent people from accessing the award when they should be able to claim it. It means a wide range of evidence can be used by claimants (and their legal representatives, if relevant) to put together their application. We will work with IBCA to publish examples of evidence that can be provided to help guide claimants in this process.

We have also carefully considered the ideas in the consultation for how we might expand eligibility for the Exceptional Loss award to include people who never earned but who, on a balance of probabilities, were likely to have earned higher than average if they had not been infected. We have thought carefully about how to ensure that any changes would be fair and allow compensation to be paid without further delays.

Calculating future loss will always involve making some assumptions about how exactly someone would have gone on to succeed in their future career. This becomes even more speculative where a person does not have any earning history. In a court, a judge makes a personal judgment based on a person’s situation which may include, for example, their educational background, character and ambitions. This level of assessment requires expert opinion and judgment and the outcomes of such an assessment are unique to each individual situation.

The difficulties of doing individual assessments as part of the compensation scheme were recognised in the Inquiry's second interim report, where the Inquiry noted that a scheme that "provides individualised assessments to each claimant…is to be avoided". Because of the way the tariff-based compensation scheme has already been established in law, it is not possible for IBCA to undertake this type of assessment.

We considered the suggestion to make the Exceptional Loss award available to people who can show certain professional or educational qualifications. We understand, for example, that many people with university-level qualifications may have gone on to have careers that paid above average salaries.

However, we share the concerns that some people raised in the consultation about the unfairness of this option and the disadvantage this would create for example for people choosing high-earning vocational career paths for which university qualifications were not needed. We also want to avoid creating disadvantages both for people whose socioeconomic background made them less likely to go to university, and for people infected early in life before they had the opportunity to finish their education.

We are committed to making the compensation offered through the Scheme as fair as possible, and for the reasons set out above, we cannot see a way that we could make changes related to specific cohorts in a way that was fair. No further changes will therefore be made to the eligibility requirements for the existing Exceptional Loss award.

However, we recognise that in some cases, people were about to take the next step towards a higher earning career but were unable to do so because their infection made them unwell. This may have been the case, for example, for people infected early in their career who were not able to take up a job after receiving an offer within a high-paying profession. We acknowledge that on the balance of probabilities, people in such cases would have been likely to earn more than what is assumed by the core route Financial Loss award, and that is therefore appropriate to give people in this circumstance more compensation.

To recognise this, we will pay a supplementary flat-rate award of £60,000 to people who can show that they had recently started or been offered a job where the median salary is more than 10% higher than the national gross median, according to the 2023 Annual Survey of Hours and Earnings. Claimants will not need to prove a specific salary; IBCA will use national statistics for that career to see if it qualifies. This award is equal to approximately two years of the highest level of financial loss under the Scheme's core route and acknowledges that the infection harmed their career potential. This award is for those who cannot provide the required evidence of actual past earnings. It will be given to people on top of their full core Financial Loss award.

This is a supplementary award that will be added to the person's core award and any other supplementary award they are due because of a severe health condition. So for example, someone who was infected and diagnosed with HIV at age 20, having recently received an offer to take up a qualifying job, would receive a core Financial Loss award of £29,657 (reduced by 50% after retirement) for each year of their life from 20 onwards, with an additional payment of £60,000 on top of that.

We recognise the concerns raised about people who were infected as children who may have lost the opportunity to carry on with their education or even reach the point of embarking upon their chosen career. Section 8 of this document explains the changes we will be making to address this issue.

Section 6: Supplementary Awards for Affected People

Inquiry recommendation: *"The Minister give consideration to there being a supplementary route for people affected. This could include opening the supplemental award for severe psychological harm to people affected. He should involve parents, children, siblings, partners and carers, and their legal representatives if wished, in this consideration."*

Summary of consultation responses

Most respondents provided feedback relevant to all three free-text questions (One, three, and four). To ensure every insight was captured, we analysed responses based on their content rather than the question they were written beneath. For example, if a respondent suggested eligible groups in Question one instead of the dedicated Question three, their view was still fully recorded. The responses we received to the questions about this topic were broad. For this reason, in this chapter we explain what key themes we identified from responses rather than say what percentage of respondents raised a specific topic with us. The exception to this is Question two where people were asked to respond with either 'yes', 'no' or 'don't know'.

Designing a supplementary route for affected people

245 respondents chose to answer **Question one**, which asked how we could develop a supplementary award for affected people that would work within the existing principles of the Scheme and therefore avoid lengthy individual assessments of people's circumstances. Most respondents shared their views on the principles of an affected supplementary route, the value of potential supplementary awards, and the nature of evidence requirements. Many respondents were supportive of a tariff-based supplementary route for affected people that was categorised by clearly defined groups (rather than a more individualised approach that looks at people's personal circumstances). Many also felt that a supplementary route for affected people should be simple to deliver and avoid delay. They felt it should not require any new evidence or assessments from applicants to prove they qualify for a supplementary award. For example, many respondents suggested that evidence provided to IBCA for the core award, or data held by IBSS should be used to prove eligibility for supplementary compensation.

In contrast to this, a few respondents supported a supplementary route for affected people but disagreed with a tariff-based approach, taking the view that there should be individualised assessment and new evidence submitted to satisfy eligibility requirements.

A few respondents disagreed entirely with the idea of a supplementary route for affected people, explaining that they felt implementing a tariff-based supplementary route would be challenging, if not impossible without either intrusive conversations or a new, individualised assessment process.

In terms of how compensation should be provided, some suggested that an affected supplementary award should be given to eligible people as a fixed lump sum. A few responses suggested annual fixed tariffs, where compensation would be calculated per year of financial loss or per year of the relationship with the infected person. Some respondents proposed specific award amounts for the groups of affected people they suggested should qualify for a supplementary award. Suggestions varied between £10,000 - £15,000 for all affected people, £10,000 - £20,000 for those affected while under 18, a flat-rate of £50,000 - £100,000 for bereaved partners, £50,000 for parents, rising to £200,000+ for bereaved parents, and £2,500 - £5,000 for siblings.

A few suggested additional awards should be given under all categories of award, a few proposed additional awards should be given under a Financial Loss category of award.

A group-based supplementary route for affected people

353 respondents chose to answer **Question two** which asked respondents to select ‘yes’, ‘no’ or ‘don’t know’ on whether they would support a group-based supplementary route, which did not require any individual assessment of eligibility. Of these respondents, 262 (74%) said yes, they supported a group-based approach that avoids individual assessment (in other words, that having evidence belonging to a specific group is the only eligibility requirement). 28 (8%) did not support this approach. 63 (18%) respondents said they did not know.

We think these responses indicate clear support for a group-based supplementary route for affected people.

Groups of affected people already established by the Scheme

237 respondents chose to answer **Question three** which invited respondents to specify, in a free-text box, the specific groups of affected people they believed should qualify for a supplementary route, if they supported this option.

Currently, the amount of compensation affected people get is determined by two main factors: the severity of the infection their loved one had, and their relation to them. Partners, parents, children, siblings and carers are all eligible for compensation.

Most respondents based their answers to this question on which of these existing cohorts of affected people they felt should receive more compensation. Many suggested that one or more of these existing, broad cohorts of affected people should be eligible for supplementary compensation. Many others suggested that only some members of these groups should be eligible for supplementary compensation (for example, some respondents suggested that parents should receive more compensation, but only if their child had died).

Many respondents felt that children of infected parents should, in particular, be eligible for a supplementary award. Of these respondents, some suggested a more narrow qualifying group of children, and gave a few different ideas about what this group should be. Some suggested children who were under 18 when their parent was infected, or who were a ‘young adult’ at the time their parent was infected. Some believed children who were bereaved by their infected parent should be eligible for a supplementary award. More widely, many suggested that anyone who was affected while under the age of 18, regardless of their relationship to the infected person, should be eligible for a supplementary award. Often, respondents explained they felt this was appropriate due to the additional psychological harm, loss of education, and 'impact on child development' caused by being affected in childhood.

Fewer people mentioned partners compared to those who mentioned children, but many respondents still felt that partners should get more compensation through a supplementary route. Some suggested that partners should qualify if they were in a particularly long-term relationship with their infected partner, if they also acted as a caregiver to their infected partner, or if their partner died early because of the infection. People explained that these partners should receive a supplementary award because they have dealt with the heavy burden of caregiving, increased psychological harm, loss of income, and the pain of losing a loved one.

Many people suggested that parents whose children were infected should also get an extra payment. Answers that made this suggestion tended to focus on parents whose child died due to the impacts of infected blood. Some suggested that a supplementary payment should specifically go to parents whose children died before they turned 18 to help cover the money they lost when they were prevented from working due to grief, or providing full-time care prior to their child's death. Respondents explained that these parents should qualify for a supplementary award because of the heavy emotional toll, the cost of caregiving, and the trauma caused by infections like HIV or difficult treatments like interferon.

Fewer respondents mentioned siblings than children, partners or parents, but some felt that siblings should also qualify for a supplementary payment. There was a particular focus on siblings who felt 'secondary neglect' where their parents were focused on their infected child, household trauma, bereavement and premature responsibility and caregiving. The main reasons given by these respondents were that a sibling's illness often disrupted their education, caused long-term emotional distress, or led to them facing social stigma.

Some respondents believed affected carers should qualify for a supplementary award due to the impact of caregiving, psychological harm and the stigma they faced as a result of the infected person's infection.

Other experiences faced by specific groups of affected people

Many responses stated that affected people who were bereaved because of the loss of an infected person, whatever their relationship to them, should qualify for a supplementary award. While some felt this should apply to all bereaved affected people, others suggested it should focus on specific affected groups. These included bereaved partners, children, parents, or siblings. These specific bereaved cohorts were suggested for reasons such as the aggravated grief of losing a loved one to infected blood and the instability it caused and, for bereaved partners, the impact of being left as the sole parent to care for their children. There was also a specific mention of children who were very young when their parents died, and those who lost a loved one much earlier than expected due to infected blood.

Responses commonly reflected the impact of infection on the ability of affected people to enjoy a normal life or daily activities. Many respondents thought people who had to quit their jobs or lost money in their own right because of the infection should qualify. Others highlighted children whose education was disrupted. A smaller number of people also mentioned that some affected people themselves lost the chance to have children due to the impact of the infection on their life, and suggested an award to recognise that loss.

Some respondents suggested that affected people who suffered their own health or mental health problems due to infected blood should qualify for a supplementary award. Others thought that affected people who had taken on extra caregiving should receive a supplementary payment to make up for the money they lost. They suggested that to qualify, IBCA could use medical records or government records of Carer’s Allowance.

Some respondents also suggested that anyone who lived with an infected person should qualify for an extra payment. Some included a suggestion that they would have had to live together for a certain amount of time to be eligible.

Many other respondents said that those who looked after someone with a very severe infection or a serious underlying health condition should qualify. Some of the examples given included cases where the infected person had HIV, was infected for a long period of time, had to go through difficult interferon treatments, or where the infected person has received ‘Special Category Mechanism’ payments.

Nature of evidence requirements

225 respondents chose to answer **Question four**, which asked respondents who thought certain groups should be eligible for compensation what pre-existing evidence IBCA could use to determine whether particular applicants belonged to that group.

Most respondents agreed that IBCA should use pre-existing evidence and records to determine eligibility, with examples given including: medical records, Inquiry records, official, government and legal documents (birth, marriage, and death certificates). To prevent retraumatisation, most preferred to avoid both intrusive evidence requirements and individualised assessment.

Government response to the consultation

How the compensation scheme will change

Some affected people will receive more core compensation. To reflect the unique and long-lasting impact of their experiences, the following affected people will receive a 50% uplift to their Injury award:

Children and siblings affected whilst under the age of 18, so that those affected in childhood receive more compensation;

Bereaved parents whose infected child died under the age of 18; and

Bereaved partners

We can see from the consultation results that the mental and emotional harm people have suffered must be better recognised. To help us understand how best to do this, we asked the TEG if they felt the current compensation payments available to affected people were sufficient for the groups of people the consultation raised had experienced additional psychological harm.

The TEG advised that while the standard payments are already higher than what a court would likely award for the vast majority of affected people, having reviewed the consultation responses, they agreed there was a strong moral case for increasing the Injury award by 50% for children and siblings who were affected before they turned 18.

We will therefore introduce an **enhanced core Injury award for children and siblings affected while under the age of 18, so that those affected in childhood receive more compensation.**

The uplift will be given to eligible people alongside their core route claim (unless they have already received their core route compensation, in which case IBCA will review their claim to work out if they are owed more compensation). People told us it was important that receiving more compensation did not require any more assessment or evidence. Providing an ‘uplift’ in this way means IBCA does not need to make any further assessment of someone’s circumstances, or ask them for any more evidence, to work out if they are eligible.

We have also introduced a separate uplift to the Autonomy award for those who were infected in childhood (see Section 8).

Bereavement

Many respondents told us that losing a loved one to infected blood brings a level of grief and trauma for any bereaved affected person, and that the Scheme does not fully recognise this. Respondents particularly highlighted how partners, parents and children face a deep psychological impact that lasts a lifetime. For partners, this often means losing a future with the person they expected to grow old with, or suddenly having to raise children as a sole parent.

A few suggested that a Financial Loss award should be introduced to give more compensation to parents whose infected child died before the age of 18. We received many responses that highlighted the unimaginable pain of losing a child. We have listened very carefully to these calls for better recognition within the compensation framework.

Unfortunately, we do not think it is possible to implement a Financial Loss award for affected people. This is because a core principle of the Scheme, based in part on how the courts award compensation, is that affected people do not receive Financial Loss and Care awards in their own right, due to these two awards being tied to the physical infection itself. For example where a bereaved child or partner receives a core Financial Loss award, it is intended to recognise the financial support they would no longer receive from the deceased infected person, rather than compensating them for their personal loss of earnings. Bereaved partners and children do receive a dependency award (because they would have expected to benefit financially from the infected person when they were alive), and an additional supplementary Financial Loss award is available to other bereaved affected people who can show they were financially dependent on the deceased infected person.

We understand that the harm described by respondents is not merely financial, but is a deep psychological injury from the bereavement, and technical constraints should not result in a lack of recognition. Therefore, while we could not implement a Financial Loss award, we have looked at what we could do instead to formally compensate for the traumatic experience of bereavement for parents and partners.

Therefore, we will also introduce an **enhanced core Injury award** to the following specific bereaved groups, in light of consultation responses:

- **Bereaved parents whose infected child died under the age of 18**
- **Bereaved partners of infected people**

This uplift means more compensation will be available to parents whose child died before the age of 18 because of infected blood, before 14 April 2026. It also means more compensation will be available to eligible partners whose infected partner passed away before 14 April 2026. We have chosen this cut-off date to protect vulnerable people. We want to make sure there is never a situation where someone might feel that their own death would result in a higher financial payment for their family.

To be eligible for this uplift, the infected child or the infected partner who passed away must have had an infection severity band that the TEG advises was more likely than not to have been the cause of their death. This means they had to have had HIV, cirrhosis, decompensated cirrhosis, liver cancer, or an acute Hepatitis B fatality. All bereaved partners currently registered with an IBSS will automatically be eligible irrespective of the infected person’s severity band at the point of their death.

Enhanced Core Injury award - amounts

All three uplifts apply to the **Injury award**. This category of award compensates for the physical and mental injury, emotional distress and the hurt to feelings caused by being affected by infected blood. In the consultation, many respondents told us that the existing core route payments did not fully recognise this deep trauma and the way lives were altered by these experiences. We have listened to these concerns, and these additional payments are designed to address them.

Consultation feedback showed a compelling case for additional awards for certain groups of affected people, and the TEG supported this. In the absence of comparable case law, the TEG recommended a 50% uplift to the Injury award for these specific groups of affected people.

The new amounts are set out below:

Infection severity	**Sub-Group**	**Core Injury award**	**Enhanced award (50% uplift)**
Affected people where the infected person had Hepatitis C/Hepatitis B (Chronic)	*Affected under 18 (siblings)*	£20,000	£10,000
	Affected under 18 (children)	£20,000	£10,000
Affected people where the infected person had Hepatitis B (Acute, where the infection resulted in a fatality in the acute period, or where reactivation of Hepatitis B infection resulted in acute liver failure and a fatality within 12 months) or Hepatitis C/Hepatitis B (Cirrhosis) or Hepatitis C/Hepatitis B (Decompensated cirrhosis) or HIV or co-infection	*Affected under 18 (siblings)*	£22,000	£11,000
	Affected under 18 (children)	£40,400	£20,200
	Parents of deceased children who passed away under 18	£65,400	£32,700
	Bereaved Partners	£86,000	£43,000

The award amount for affected children depends on how severe the infection was during the affected person's childhood. For example, if the infected person had chronic Hepatitis C while the affected person was a child, and then the infected person developed Cirrhosis when the affected person was an adult, the affected person will receive an uplift based on the infected person having chronic Hepatitis C. This means they will receive an Injury award totalling £50,400, made up of a £40,400 core Injury award, and a £10,000 enhanced Injury award.

Creating a new Supplementary Route for Severe Psychological Harm

The Inquiry asked us to look at whether a supplementary route could be implemented for affected people. This would be a new route to compensate for 'exceptional cases' where the core payments might not cover someone's specific losses or needs. To use a route like this, applicants would normally have to provide a lot of evidence, such as medical records or financial documents, as required by the supplementary route for infected people.

While a few people were supportive of individual assessments to get more compensation for psychological harm, most people told us that having to retell their story is painful and re-traumatising. The feedback from the consultation was very clear: 74% of people who responded preferred a 'group-based' approach where the trauma they have experienced is recognised and compensated automatically, without the need for difficult medical assessments or extra paperwork. The TEG supported this position, highlighting the clinical challenge that IBCA would face in establishing a causal link between a person's infection and their poor mental health if individual assessments were used. The TEG was also concerned that assessments of psychological harm would be re-traumatising for victims. **We have listened to the views shared in the consultation and the TEG's advice and we agree that a route requiring more psychological evidence from applicants would not be an appropriate way to award affected people more compensation.**

Recognising the sacrifices made by affected people

Some respondents detailed the profound personal costs faced by family members, many of whom felt they had to leave their jobs or saw their career trajectories permanently altered. Some people suggested there should be a supplementary route that provides additional compensation where this can be evidenced.

When we looked at how we could address these losses, we looked at the recommendations from the Inquiry. Both the Inquiry and the previous Expert Group's view, which the Government adopted, was that financial loss for affected people should be focused on financial dependency. This means making sure that those who relied on an infected person's income are supported after that person has passed away. To go beyond this and cover every type of career loss for family members would require long and difficult assessments of past earnings and career potential. This is exactly the kind of evidence-heavy process that most respondents told us they wanted to avoid.

Many respondents told us that there should be an extra payment for people who have taken on a lot of caring responsibilities. Some shared that providing long-term, unpaid care for a loved one is very difficult, can lead to 'caregiving anxiety' and that seeing someone you love deal with a serious illness can be enormously stressful.

Caring responsibilities are already recognised through the infected person's Care award. This is money to cover someone's past and future care costs. It is given to the infected person, and they have the right to transfer some or all of it to the family members or friends who are looking after them, or who have looked after them in the past. While we understand the concern that this transfer is not possible in cases where the infected person has passed away, creating a separate supplementary award for carers would risk 'double-counting' where we have already compensated the infected person (or their estate) for the care that they will have received, or will receive in the future (often historically provided by family members without charge).

The experience of those affected by severe and terminal conditions

Some people suggested that there should be extra payments for those who lived with an infected person when their illness was particularly serious, or where the infection was especially severe. Examples people gave in their responses include cases where the infected person had HIV, was infected for a long period of time, had to go through interferon treatments, or where the infected person has received 'Special Category Mechanism' payments. We acknowledge this strength of feeling from respondents about the effect that living together whilst the infected person was ill, or the impact that a severe infection may have had on affected people. We agree it is right that people receive different amounts of compensation depending on the effect the infection was likely to have on their life, as far as this is possible within a tariff-based compensation scheme. Ways that the Scheme already achieves this are:

Recognition of cohabitation: The Scheme already takes living together into account. For example, to be eligible as an affected person, you often have to show that you lived with the infected person. We also already pay higher amounts to siblings who lived with their brother or sister after they were infected. This means the impact of living in the same home is already built into the core payments.

Recognition of infection severity: Injury awards for affected people are already based on how serious the infection was. Payments are higher if an affected person's loved one had a condition like cirrhosis, liver cancer, or HIV. This is specifically done to recognise that in these cases the infected person's illness is so severe that it resulted in, or is likely to result in, an early death. Additionally, higher infection severity results in a larger Care award - infected people can direct any portion of their Care award to those who provided their care.

A universal compensation uplift

Some consultation responses suggested all affected groups should receive more compensation. This would mean that no specific group of people would receive more compensation as a result of what happened to them, but that every eligible affected person received more money than they will currently get.

We looked into whether this was possible, as we know that everyone affected by infected blood will have suffered mental and emotional harm. This is why all affected people already receive £10,000 as part of their Injury award, which specifically compensates them for psychological harm. This was recommended by the previous Expert Group.

However, we felt that a blanket increase would fail to recognise the very different and unique challenges faced by different groups of affected people. The consultation responses made it clear that certain groups face specific types of harm that deserve their own individual recognition. By focusing the additional awards on specific groups, we can make sure the compensation better reflects the different ways people's lives have been affected.

Section 7: Unethical Research

Inquiry Recommendation: *"Where there is evidence that an individual was the victim of unethical research practices IBCA should be authorised to make an unethical research practices award to that individual.*

When considering the evidence IBCA applies the wider definition of research explained in the Infected Blood Inquiry Additional Report chapter on Unethical Research.

The Minister consider whether the £10,000 (£15,000 for Treloar's pupils) should in justice be increased and further decides what sum he considers accords most closely with the general public's sense of justice and fairness in respect of an individual being subject of research without informed consent."

Summary of consultation responses

Question one asked respondents *whether they agreed that all infected people who received treatment for a bleeding disorder in the UK in 1984 or earlier should be eligible for an Unethical Research award without needing to produce further evidence*. We also invited free-text responses for those who wanted to give further detail to explain their answer.

There were 333 responses to this question, with the majority in favour of the proposal to expand the scope of the award. 303 (91%) of respondents were in agreement with the proposal based on the multiple-choice question.

Of the 245 free-text question responses, those who supported the proposal mainly did so for two reasons: the fact that more people will now be eligible and the reduced need for complicated paperwork. Many respondents felt that unethical research was widespread and experienced by many infected people, so expanding the criteria to include more patients with bleeding disorders was a better proposal. Respondents also strongly agreed that removing the 'burden of proof' was fairer for applicants. They explained this was because it meant people would still receive an award even if they were never told they were part of a study or if they can no longer find their historical medical records.

While most people who answered the multiple-choice question supported the new proposal, a closer look at the free-text answers reveals a range of opinions about the awards. Some respondents agreed with the proposal but raised specific concerns about how awards would be administered. These concerns included the types of evidence needed and the specific dates used to decide who is eligible.

One notable issue was the proposal that eligibility should be limited to those treated in 1984 and earlier, with 10% of free-text respondents disagreeing with this part of the proposal, even if they agreed with the other suggested changes to scope.

Our proposal suggested offering the Unethical Research awards to people who were treated for bleeding disorders before 1985. This specific year was chosen because the latest medical study identified as unethical by the Inquiry took place in 1984. To be classed as unethical, a study had to meet certain rules, such as changing a patient's treatment without their full permission or performing extra invasive tests, like liver biopsies, that were not actually needed for their care. It also included cases where doctors failed to tell patients about test results that should have changed the way they were treated.

However, many people who shared views felt that limiting eligibility to those treated in 1984 and earlier was a mistake. Reasons given were varied but fell into three main themes: some thought the date was incorrect because of trials that happened in the 1990s, others due to the continued use of older blood products in 1985, and others due to a specific example of a patient trial that took place in 1985 found in a recent report. We looked at the trials from the 1990s when originally setting the date range and do not believe they fit the criteria for unethical research. However, the other two issues raised make a stronger case for extending the date to include 1985.

Question two asked respondents *whether they agreed that, given the particular circumstances experienced by students at Treloar’s, it is appropriate for them to receive both of the awards, amounting to £25,000 based on the original award values*. Again, we invited free-text responses for those who wanted to give further detail to explain their answer.

This question asked whether students who attended Treloar’s should receive both awards, amounting (on the basis of the existing award values) to a £25,000 award. Out of the 328 people who answered the multiple choice part of this question, 259 (79%) agreed with the proposal. 34 (10%) said they did not know, and another 35 (11%) disagreed.

Many people who supported the idea felt that attending the school placed pupils in a unique position. In the free-text section, 85 people pointed out that the lack of parental oversight at the school made the situation at Treloar’s different from other circumstances in which someone might have been subjected to unethical research. Another 50 people used the free-text box to confirm that they agreed with the proposal in principle, though they did not go into detail about why they felt this way.

Responses that suggested disagreement with the proposal gave a range of different reasons. 20 people felt that £25,000 was simply not enough money given what the students went through. 25 other people argued that what happened at Treloar’s was similar to what happened to patients at other hospitals, so everyone should receive the same amount of compensation. Additionally, a few people suggested that instead of focusing on one school, any child under the age of 18 who was part of unethical research should get a higher payment.

Question three asked respondents *what approach could the Government take to determine an appropriate value of the Unethical Research award*. For this question, we gave a free-text box so respondents could set out their views.

228 responses were given to this question. Many respondents felt the current awards were too low, but did not suggest ways to determine or calculate an appropriate amount in line with the Inquiry’s recommendation. Where people did suggest approaches to determining award amounts, 38 respondents showed support for using legal comparators, and a few suggested alignment with other existing compensation schemes. Some suggested novel approaches,

including benchmarks which may be difficult to implement, such as equating the value of the wrong to the salary of a medical professional or the market cost of research primates. Others proposed resource-intensive individual assessments to determine award amounts.

Some people raised concerns about how vulnerable groups, especially children, were treated under the current proposal. This feedback was very similar to the comments made about the Treloar's school award. In total, 11 respondents suggested a 'tiered' system that would change the amount of compensation given based on how much a person was affected by unethical research. Additionally, 10 participants specifically called for children to receive higher awards than adults. This idea was supported by 13 other respondents in the section about Treloar's, who argued that any child under 18 subjected to unethical research should receive a higher payment than adults. This was also raised by the Recognised Legal Representatives (RLRs) in an engagement session on this topic, pointing out that while adults might have been able to understand a medical study and agree to it, children were completely dependent on others and never had the chance to say no.

Government response to the consultation

How the compensation scheme will change
Anyone who received treatment for a bleeding disorder in the UK before 1986 will now be eligible for additional compensation through the Unethical Research award. The value of these awards has increased.

Those who were treated as adults will receive an award of £30,000.

Those who were treated as children will receive an award of £45,000.

Children who were treated whilst attending Treloar's will receive an award of £60,000.

Expansion of the award scope
It is clear from the consultation that most people agree with the proposal to expand eligibility for Unethical Research awards to include all infected people who received treatment for a bleeding disorder in the UK before 1985. We will therefore expand eligibility in this way. This means people will not have to prove they were part of a specific medical trial, but instead the award will be available to all patients treated for a bleeding disorder before 1986. This change acknowledges that many people were subjected to research, such as extra blood tests or changes in their treatment, without their knowledge or consent. By removing the 'burden of proof', we hope to make sure that people who cannot find old medical records (or whose records were destroyed) or were never told they were part of a study are no longer unfairly excluded from receiving support. This expansion is also a response to the practical reality that linking individual patients to specific studies from decades ago is nearly impossible. We have therefore taken an inclusive approach to eligibility, so that the award is easy to administer.

We understand this approach could lead to some people receiving the Unethical Research award when they were not subjected to unethical research. We believe it is very important to avoid a situation where someone who was subjected to such research is unable to receive compensation because the evidence of what happened to them is not available. The approach we have taken to eligibility makes sure that our focus is on providing compensation in the most operationally straightforward way rather than requiring victims to provide evidence that likely no longer exists.

We will change the current date range for the award, so that it includes all treatment up to the end of 1985. While the original proposal stopped at 1984, consultation responses have pointed to evidence from the Inquiry which showed that 1985 was a major period of transition for bleeding disorder treatment. During this time, doctors were transitioning from older blood products to newer, safer heat-treated versions. Because both types were being used at the same time, some doctors may have compared the results of the two products on their patients without asking for permission. Since some specialists continued using the older products well into 1985, extending the date ensures that no one who might have been part of these comparisons is missed.

Treloar's award

We proposed that students who attended Treloar's and were victims of unethical research should be eligible for both the standard Unethical Research award and the Treloar's award, totaling £25,000. We proposed this as a way to better recognise the unique circumstances of the school, where medical treatment and research were conducted in an environment where children were separated from their families.

After carefully considering the consultation responses, where 80% of respondents agreed that Treloar's students should receive £25,000 (equivalent to receiving both awards), **we agree that people who attended Treloar's should receive more compensation for what happened to them**. As set out above, it is clear from the consultation that respondents felt Treloar's was a unique situation. Many respondents highlighted the lack of parental oversight as a defining factor that differentiated the school from other clinical settings. However, we believe the institutional nature of Treloar's created a unique environment that justifies the specific recognition.

We acknowledge the feedback from several respondents who felt that, whilst people who attended Treloar's should receive both awards, £25,000 still does not fully reflect the gravity of the suffering endured at Treloar's. The Unethical Research awards intend to compensate for the breach of a claimant's right to consent to be a part of research, recognising the loss of personal autonomy (their right to make their own choices). These are paid on top of the core Autonomy award, which compensates for impact to personal and family life.

We have therefore decided to increase the total value of the award to £60,000. This will mean that any student who attended Treloar's and was a victim of unethical research before 1986 will receive a total of £60,000 as an additional Autonomy award for unethical research.

Determining award values

In the consultation, we originally proposed award values of £10,000 for the general award for unethical research and a combined £25,000 for students of Treloar's (compared to the £15,000 single award previously). We asked for views on the most appropriate way to determine those values to ensure they aligned with the public's sense of justice and fairness.

Many respondents felt the original figures were too low. They offered a range of suggestions for how to calculate a fairer amount, including using legal comparators or aligning the values with other existing compensation schemes. As outlined above, a key theme that emerged from the consultation was the experience of people under 18, who were unable to consent to research, where consent was asked for.

After reviewing the consultation, we have decided to significantly increase the value of the compensation available to victims of unethical research.

We will also introduce a new tier of award for people who were victims of unethical research during childhood.

For adults who were victims of unethical research, the award value will be increased to £30,000. However, we have listened to the strong arguments provided by respondents and raised in conversation with the RLRs who highlighted that children were in a uniquely vulnerable position. To reflect this, we are introducing a Childhood Unethical Research award of £45,000 for any person who was under the age of 18 at the time of their first treatment.

By setting the award for children at a higher level, we are recognising the impact of these practices on those who lacked any agency. As previously noted, students who attended Treloar's will receive the highest tier of £60,000. This accounts for the exceptional circumstances at the school, where the absence of parental oversight created a unique environment where unethical research took place.

In setting these awards, we have considered how a court would generally approach cases like these. While a tariff-based scheme does not allow for the same detailed consideration as a court hearing would, we have endeavoured to ensure that the awards are set at a commensurate level.

Section 8: Additional Issues raised in the Consultation

The final chapter of the consultation invited respondents to raise any other issues with the Scheme that were not covered in the Inquiry's Additional Report. The specific question we asked was: *"Are there any other issues you would like to raise about the Scheme that have not already been considered by the Inquiry in preparing its Additional Report on compensation?".*

Summary of consultation responses

Of the 710 responses to this question, 416 (59%) provided more detail. 35 of these provided no specific answer (for example, they simply answered 'No' or 'Don't know'). The remaining responses gave wide-ranging views on different elements of the Scheme. Many participants shared their lived experience of the scandal. Some respondents suggested new changes, while others commented on the structure of the Scheme's set payments (tariffs) or how IBCA delivers them. Finally, some respondents had comments or questions about the compensation that is available to infected and affected people.

Because the issues raised in this section were so wide-ranging, and because some respondents covered lots of different points or questions in a single answer, this chapter sets out the key themes that were raised in people's responses, rather than listing the exact number of respondents who chose to raise a specific point.

Scheme Design, Tariff Structure and Awards

Many respondents had comments on the way the Scheme works for claimants, and the amount of compensation available. These comments included concerns or questions about:

- The tariff-based structure of the Scheme and that it leads to fixed award amounts.
- Inequalities in how different groups were treated, such as those with HIV compared to those with Hepatitis C.
- The lack of interest or indexing on the core tariffs. Respondents explained that those who have received compensation earlier from IBCA have had greater opportunities to invest their compensation and see a further return from this.
- Specific medical conditions and how these have been recognised or addressed through the Scheme. This included: the impact of Variant Creutzfeldt-Jakob Disease (vCJD); thalassaemia; early menopause; esophageal varices and infections caused by sexual contact.
- The recognition of acute Hepatitis B. Two main areas of concern were: the adequacy of award amounts for people who had acute Hepatitis B and died, and the eligibility criteria for people infected with Hepatitis B.
- The way financial loss compensation is calculated for estates of infected people. These responses highlighted a feeling that there was a difference of treatment between living and deceased infected people.

Delivery, Administration, and Transparency

Some respondents said compensation is not being delivered fast enough. Respondents who felt this way often set out specific issues occurring as a result, including re-traumatisation from having to wait for an invite to claim. Many responses criticised the order in which victims are invited to apply for and receive their compensation payments. The majority of these responses identified deceased and unregistered infected people as the cohorts that had been negatively affected by decisions on sequencing. Many responses criticised the evidence required to claim compensation, expressing frustration about how cases are handled when people do not have the right evidence, particularly in cases where medical records were missing or previously destroyed.

However, some respondents also praised IBCA's claim process, including the relationship they had with their claims manager.

Impact on Children and Generational Harm

Many respondents felt there had not been enough consideration given to children who were infected, or affected, and the impact this had on their families and their own childhood. The majority of these responses made reference to loss of potential, i.e. that childhood infection derailed educational/career attainment. Respondents felt that this was not sufficiently covered by the core compensation on offer.

Proposals for New and Enhanced Award Categories

Several respondents used this section to advocate for additional categories of awards. Respondents outlined specific gaps where they feel the current tariff structure does not recognise the full extent of harm caused by the infected blood scandal and the lived experience of the community. This included suggestions for dedicated awards covering: loss of life, loss of potential, the delay the Hepatitis B community feel they have suffered, community advocacy, and victimisation.

Consultation Process and Engagement

Some respondents said the consultation was difficult to understand and other people worried it would cause more delays. On the other hand, other people welcomed the chance to share their views.

Common Questions

Some respondents had questions or feedback about how the Scheme is currently designed, regulated, or delivered by IBCA. We recognise that the Scheme is complex and elements of it can be difficult to understand. To help with this, we have separately published a guide explaining the most common questions raised by respondents.

Responses unrelated to the consultation

Some respondents shared views on specific issues that do not directly relate to the Scheme and the proposed changes, for example: concerns about how the probate system operates in England and Wales, NHS training and guidance, or taxation.

Government response to the consultation

How the compensation scheme will change
Because of the clear call for more compensation to reflect the impact of an infection on someone's childhood, people who were infected aged 18 or under will now receive more compensation. Their core Autonomy award will be increased by 50%.

Increased awards for those infected as children
We will make further changes to the Scheme to recognise the specific impacts of infected blood on children who were infected under the age of 18. This is in recognition of the concerns raised across the consultation about the 'loss of potential', impact on future earnings and the increased trauma that a person infected as a child would have likely experienced (which goes beyond the core tariffs). **We will therefore introduce an enhanced core Autonomy award for people who were infected aged 18 or under**.

This award will provide a 50% uplift to the core Autonomy award, calculated based on the highest severity level of infection reached during childhood. For example, if the infected person had Chronic Hepatitis C while in childhood, but did not progress to Decompensated Cirrhosis until later in their life, the uplift will be based on the Chronic Hepatitis C severity level. This means they will receive an Autonomy award totalling £70,000. They will receive a core Autonomy award of £50,000 and an enhanced Autonomy award of £20,000. For the purposes of this uplift, we only look at the severity levels that occurred before the infected person turned 18. While the TEG noted the lack of a strict legal precedent for such an uplift, this 50% figure seeks to balance the profound impact experienced by all victims with the disproportionate loss of autonomy suffered by children. The table below outlines the uplifted awards based on infection severity.

	Acute Hepatitis C	**Hepatitis C or B (Chronic or Cirrhosis)**	**Hepatitis B or C (Decompensated cirrhosis and/or liver cancer and/or liver transplantation)**	**HIV**	**Co-infection**
Current Autonomy Award	£10,000	£40,000	£50,000	£60,000	£70,000
Enhanced Autonomy Award (50% uplift)	£5,000	£20,000	£25,000	£30,000	£35,000

The uplift is applied specifically to the Autonomy award because this category recognises the distress and suffering caused by the impact of the disease, including significant interference with family and private life. The uplift will provide more compensation for the unique impacts of childhood infection, such as increased psychological harm, the disruption of education, the long-term effect on earning potential, and the loss of a carefree childhood.

The uplift will be granted automatically to people infected in childhood using pre-existing information already held by IBCA, specifically the person’s date of birth and date of infection.

In addition, as a result of the consultation, we have:

- Shared feedback raised under ‘**Delivery, Administration, and Transparency’** with IBCA. We have also shared feedback raised under ‘**Responses unrelated to the consultation’** with other relevant government departments, where feedback relates to areas that they are responsible for (for example, like inheritance tax).
- Asked the TEG for advice on whether the Scheme appropriately compensates people for the experience of early menopause brought on by infection or treatment for Hepatitis, and esophageal varices as a result of their Hepatitis infection. We agree with the TEG’s assessment that these impacts are already compensated by the Scheme.
- Asked the TEG to reconfirm if, in line with previous advice, the compensation tariff for acute Hepatitis B is sufficient. As there have been no material changes in circumstances to support the concerns, the TEG was content that the tariff is sufficient and the eligibility criteria reflects the recommendations made by the Inquiry.
- Published a document called ‘Design of the Scheme and Common Questions’. This addresses the other points raised under **‘Scheme Design, Tariff Structure and Awards’** and **‘Common Questions**’.

Implementing The Changes: What Happens Next?

The design of the compensation scheme is set out in regulations. These regulations set out the precise requirements of the compensation that IBCA must pay people, and the different routes they need to set up for people to receive it. While IBCA operates independently to deliver the Scheme, it must do so within this existing legal framework.

This means that to change parts of the Scheme, we must first update these regulations. This process requires drafting new legislation and seeking Parliamentary approval, which means these improvements cannot take effect immediately. Until these regulations become law, IBCA is legally required to continue providing compensation based on the current rules. Our priority is to make these changes as quickly as possible so that compensation can be paid to victims without further delay, and so we can limit the number of people who will have been paid before the changes have been made, as they will need to have their claim reviewed by IBCA to give them the further compensation they are owed.

However, where we can take action now, we will. We think we can improve how we communicate and explain the Scheme to the public and to the infected blood community specifically. We hope that this document helps set out as clearly as possible what changes we are making and why. We also hope it explains why we cannot make every change that consultation respondents asked for.

We will also look again at the current ‘explainer’ document to see how we can make it clearer and easier to understand. Beyond this, we will review our entire suite of guidance to make sure the Scheme can be understood by the infected blood community. We want these changes to be as transparent as possible, therefore every change we commit to in this response will be reflected in the explainer on GOV.UK. We will continue to keep the community informed as this work progresses.

We will also pass on to IBCA the concerns raised in the consultation responses around sequencing, processing of compensation and evidence requirements.

In July 2025, the Inquiry recommended that IBCA and Cabinet Office create a mechanism for community concerns to be formally raised and responded to. In light of our commitment to community engagement and transparency, we have launched a mailbox to make things easier for people to raise concerns with either the design, or the delivery of the compensation scheme, in direct response to Recommendation 2e from the Inquiry’s Additional Report. These concerns will be considered by the relevant senior responsible officer (SRO) and the Cabinet Office and IBCA will publish quarterly summaries of the feedback received from the community alongside a Government or IBCA response. You can read more in our announcement regarding the 2e mechanism.

How We Analysed Your Responses

We recognise that many people responding to this consultation were deeply impacted and traumatised by the infected blood scandal. Because of this, it was vital that our method of analysis was robust, thorough, and respectful of the time people had taken to tell us their opinions and personal stories. To that end, multiple human reviewers considered each response and Artificial Intelligence (AI) was not used in the review or analysis of the consultation responses. Our aim was to ensure that no story, opinion, or experience was lost and that the themes we developed fully reflected the views of the people who came forward.

Overview

In the design of the consultation, we chose to use more than multiple choice and simple "yes/no" questions. We asked open questions so people could tell us about their experiences, concerns, and opinions in their own words. In research, this type of detailed written information is called "qualitative data".

We were fortunate to receive a large number of detailed written responses to the consultation. To review this large amount of qualitative data fairly and accurately, we used a formal research method called Thematic Analysis. In simple terms, Thematic Analysis is a way to systematically identify the shared patterns (which we call "themes") within people's responses. We selected this approach for its flexibility and its ability to provide a rich, detailed, and nuanced account of the lived experiences of those affected by the Scheme and its policies.

Data Collection and Sample

We received a total of 753 responses from two primary groups of people:

- Infected people: People who have been directly or indirectly infected through NHS blood, blood products, or tissue. This includes anyone, living or deceased, who has been infected with HIV, Hepatitis C and chronic Hepatitis B, as well as those who were indirectly infected through their partners or loved ones. It also includes people who had an acute Hepatitis B infection and died from their infection during the acute period.
- Affected people: People who have suffered the impacts of infected blood through their relationship with an infected person. This includes partners, parents, children and siblings, and other friends and family members who cared for loved ones with an infection without reward or remuneration. Where an eligible person has sadly died, we also heard from the personal representatives of the deceased person's estate.

Following quality assurance and validation, this was reduced to 710 responses. More detail can be found on that quality assurance and validation process below.

For the quantitative questions, where data is presented in the form of a percentage, the percentages may not total 100 due to rounding.

For the qualitative questions, there may be times where the percentage total is greater than 100%. This could occur when addressing how often themes appeared in the responses, and an individual response could discuss multiple themes.

Coding Framework and Analysis

We followed a careful process to ensure that each response was reviewed accurately and in a way that prevented personal bias of the reviewer. This section sets out each of the steps we took to review the consultation responses.

Guidance and training: We defined a standardised approach to support the team of researchers to read and interpret responses in a consistent way. This ensured that individual researchers approached the consultation with the same objective mindset; our aim was to minimise any individual researcher's personal assumptions.

Reading and coding: The consultation was divided into specific areas focussing on key research questions. For each single area, two main researchers read every single response in full. As they read, they "coded" the answers. Coding simply means labeling the specific ideas or concerns mentioned in the response. Coding provides a shorthand way to organise chunks of text by content, so topics with similar ideas can be grouped. We then used these codes to identify patterns and general themes that capture broad ideas shared between respondents and across the different research questions.

The two researchers cross-checked their work with each other throughout, to mitigate individual researcher bias and ensure they were interpreting the responses fairly and accurately. Any discrepancies were resolved through consensus. To add an extra layer of scrutiny, a third researcher reviewed a sample of the early work done by the research pairs. This "third pair of eyes" acted as a safety check, ensuring the coding was consistent.

Building the themes: Once every response had been read and labelled, the pairs of researchers grouped the codes together into broader, overarching themes. These themes captured the essence of the participants' experiences and the key ideas researchers identified they were concerned about. For example, if many people listed specific and individual concerns about how IBCA will ensure compensation is awarded quickly and fairly, these were captured under the theme of 'Delivery, Administration and Transparency'.

Before any conclusions were made or anything written up, a third researcher reviewed the final themes against the codes to ensure consistency, limit any bias and, importantly, check that nothing had been missed.

Quality Assurance And Validation

When researchers read and interpret responses there is always a risk of unconscious bias (seeing what we expect to see). By having at least two (and often three) people review each response, we ensured that the final report is informed entirely by what respondents told us.

To ensure the true feelings of respondents were captured in the analysis, an additional check was undertaken, with a focus on verifying and validating the interpretations of researchers. This check was done by a researcher who had not been involved in earlier policy development, consultation design, or analysis. By reviewing the final themes and interpretations without prior involvement in the analysis phase, this person was able to ensure that the findings were grounded strictly in the data rather than influenced by prior knowledge or assumptions.

Recognising that we were hearing from people who had experienced trauma, we chose not to collect or mandate that responses should have a unique identifier (such as a name or email address). We did this to enable the community to respond with anonymity. Because responses could be submitted without personal identifiers, researchers identified a small number of submissions where two or more responses contained identical or very similar text.

It is impossible to definitively say whether these were accidental duplicate submissions for a single person, or if they were responses from different people, who chose to use similar wording. Since the infected blood scandal affected whole families, who may have collectively considered how to respond to the consultation, we made the conscious decision to include these responses. We decided that the risk of accidentally deleting a genuine response from a victim was unacceptable. Therefore, all of the potential duplicates were read and incorporated into this thematic analysis.

During the reading process, we did, however, identify one case where a large number of near identical responses risked skewing the overall analysis. Approximately 40 responses were nearly identical (with very similar answers and consistent choices on which questions were skipped and answered). These responses were submitted over several discrete sessions, with each response generally beginning within seconds of the previous response being submitted.

Due to the high volume, including these responses as multiple separate voices would distort the final results and our interpretation. To ensure these responses were interpreted fairly, they were reviewed by a panel of four researchers.

By consensus, and on the balance of probability, the panel determined that these responses were almost certainly duplicate responses. However, we did not want to risk deleting all of them and losing potentially unique comments. Therefore, researchers read all the responses and merged the text into a single response. Our approach addressed the impact that including these duplicates would have, while ensuring we were not missing any important opinion and voice within the answers.

Using multiple coders, secondary verification, and independent review increased both the rigour and reliability of the analysis. This approach was adopted to provide the greatest opportunity to identify the true experiences and opinions of the respondents, and ensure that the final report accurately reflects the collective voice of the 710 respondents.

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