The Haemophilia Society's Compensation Consultation Response January 2026

Section 1 - The Special Category Mechanism and its Equivalents

1. ***Should infected people who have been assessed as eligible for SCM and its equivalents by one of the Infected Blood Support Schemes qualify automatically for this award?***

The following information is relevant context for our response to the entire consultation. The Haemophilia Society conducted a survey of its members on proposed changes to the compensation scheme and we will refer to this survey throughout this response. We will also use relevant email comments from members, where appropriate. The survey was sent to 2088 members via email and we received responses from 248 people in the period 23 December 2025 to 13 January 2026.

We agree with and welcome the proposal that an infected person that has been assessed as eligible for SCM and its equivalents should automatically qualify for this award.

We want to comment here on the start date of the award for those people who have been accepted for SCM or an equivalent. The proposal is that the start date of the award would be the date at which they were assessed. This raises some issues of unfairness.

Firstly, the roll out of the SCM and equivalents across England, Wales, Northern Ireland and Scotland was different in each nation. There were delays as to when people were assessed which could make a significant difference to the award they receive. In some cases, the variation in timescale was due to lack of capacity of the infected blood support schemes (IBSS) to assess people.

Secondly, the award was often given as recognition of the additional symptoms and day-to-day impact people suffered due to living with hepatitis C. These impacts were, in the majority of cases, experienced by people a long time before the SCM and its equivalents were brought into place. It took many years of lobbying to achieve recognition of the additional suffering of this category of people. We believe that the compensation for this additional level of impact should begin from when these additional symptoms manifested. It should not be diluted because the suffering of this category of people was ignored by support schemes for many years.

If the evidence used to grant SCM predates the schemes' start dates then the uplifted payments should start from the date the health deterioration was recognised by a health professional, as would be the case for a condition listed in the severe health categories.

2. Do you agree with the proposal to introduce an SCM Severe Health Condition award for living infected people who are not currently registered with an IBSS?

As a reminder, this would require people to undergo an evidence-based assessment similar to and based on the current England Infected Blood Support Scheme SCM assessment process to be eligible for this award. For this reason the

award would not be available to estates of people who were not registered with an IBSS.

We agree and welcome the proposal to introduce an SCM Severe Health Condition Award assessment for living infected people not currently registered with an IBSS. This is particularly important for groups such as those living with chronic hepatitis B, who have historically been excluded from support. However, it is essential to acknowledge the serious shortcomings of previous SCM application processes, including a lack of transparency around decision-making, the absence of a clear and trusted appeals route, and significant barriers to accessing medical evidence. These issues must be addressed as part of any new system.

We would also stress that it was no accident that the devolved schemes were different to the English system. They were developed because there was a recognition that the English scheme was far from perfect. In the devolved nations, schemes were designed with the infected blood community at their heart, shaped through direct engagement and, in some cases, formal public consultation prior to implementation. The devolved nations' approaches should be treated as the benchmark, with a strong case for reassessing people in England to a comparable standard to achieve genuine parity across the UK.

We think the same rules should apply to estates, where people were accepted onto SCM and the payments backdated to the time when the health of the person had clinically deteriorated.

3. ***Do you think the proposal to give people eligible for the award more compensation for financial loss - based on a reduction in their ability to work by 60-70% (in other words, that they are able to work less than half a 5 day working week) - is fair?***

We do not believe it is fair that the amount received is reduced after the introduction of effective treatment for hepatitis C in 2016. As we stated in our submissions to the additional Infected Blood Inquiry hearings in May 2025:

> *Most of the Society members who are applicants to the Scheme were treated before 2016 and therefore did not have the post 2016 treatment.*
>
> *As a result: not only are this cohort receiving no compensation at all for their pain and suffering consequent on the pre 2016 treatment they did have…in addition, they are having part of their compensation halved as a result of the supposed benefits of effective treatment (as defined by the Scheme) which they did not receive.*
>
> *The effect is to penalise people with haemophilia (and others) who were infected, diagnosed and treated with hepatitis C last century for no reasonable reason.*
>
> *Further, the Scheme fails to take into account that effective treatment as defined eliminates the hepatitis C virus but doesn't reverse liver damage or treat symptoms such as fatigue and brain fog, neither does it reverse the past negative effect of hepatitis C on earning ability which persists for those treated with Interferon type early treatments.*

We reiterate the submissions we made last year. It remains unjustifiable to reduce the payments for a cohort of people that never received the treatment this reduction is based on.

THS asked its members the following question:

Q2. Do you agree that reducing the loss of earnings payment to 60% after the introduction of more effective treatment for hepatitis C in 2017 is not appropriate for the bleeding disorders community as most people infected with the virus had already been treated, often with interferon, and continued to live with its impacts.

A total of 77% of people agreed with this statement, which was 186 out of 242 respondents.

When the SCM and equivalent categories were created, for good clinical reason, these payments were aligned with people who had developed cirrhosis. This was in recognition of the additional impacts of living with chronic hepatitis C. We therefore cannot accept an argument that would devalue suffering which has already been recognised. We propose that all people assessed and accepted onto the SCM Severe Health Condition award receive 80% of the full financial loss figure from the start dates as set out in question 2. This should not be reduced after the introduction of effective treatment for hepatitis C for the reasons set out in the first paragraph.

This is backed up by respondents to our survey who were asked:
Do you agree with our proposal that earnings reductions for people on SCM should be set at 80% of the national average wage, rather than 70%, as proposed by the government?

86% of the respondents agreed with this statement, which was 209 of 243 respondents.

We believe it is vital to the credibility of this compensation scheme that the hard-won recognition of the SCM and equivalents is supported in a straightforward way. This proposal enables fairer support and strips an additional layer of complexity from the process.

From a practical perspective, reducing the complexity is likely to lower the administrative burden on the Infected Blood Compensation Authority (IBCA) and allow it to process these supplementary payments more quickly.

Any changes that make the process smoother and quicker for both administrators and, most importantly, the recipients must be seen as a positive step. We are acutely aware that the current state of limbo is proving extremely damaging and frustrating for the infected blood community, who want to look beyond the compensation process towards what remains of their lives.

4*. Do you think the proposal to give people eligible for the award compensation for 6 hours a week of domestic support and ad hoc care is fair? What, if anything, might someone have experienced that would require more than 6 hours*

We asked this question of our members and received a mixed response with 46% answering ‘don’t know’, 16% responding ‘yes’ and 31% answering ‘no’.

Survey comments included:

‘*No, it is not fair. It should be at minimum the equivalent of the Level 2 care award at 16.5hours. SCM was awarded on many impacts of interferon, and the symptom profile has led to an M.E. diagnosis. In care, this represents domestic maintenance plus cooking,* *shopping, personal hygiene, regular travel to appointments, support with cognitive tasks including administration, and emotional support.'*

'I provide more than six hours support to my partner. He sleeps a lot, so I do everything. Six hours doesn't scratch the surface.'

On domestic support and ad hoc care, we believe six hours per week should be treated as a baseline rather than a ceiling. Where evidence demonstrates greater need, the scheme should be sufficiently flexible to allow access to the low care bands described in groups two and four of the severe health conditions framework.

Section 2 - Severe psychological harm

1. 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?

We accept that the core route through the injury award recognises "the mental injury, emotional distress and injury to feelings" that has been caused to everyone infected and affected. Also, the "stigma and social isolation" is recognised with the social impact award and the autonomy award recognises the "aggravated distress". This the baseline that all those infected and affected have suffered and this is an acceptance of the mental and emotional harm done.

We welcome the inclusion of those who qualified for the SCM award through the IBSS schemes based on their mental health problems etc. (section (v) as laid out in Annex c of the policy paper "Infected Blood Compensation Scheme Summary; August 2024), although later withdrawn. This will recognise the additional suffering of many that were excluded from the Severe Health Conditions award. We refer you back to the first section on SCM as to the start dates and levels of payment we believe appropriate to recompense this cohort of people.

We do however have concerns for the people who were not awarded the SCM through the IBSS schemes and were rejected from this category despite, in some cases, having clear evidence of additional mental health impact. As discussed in Section 1, there was disparity in the approach to awarding SCM across the devolved nations and we believe, in some cases, even within nations depending on the reviewers of the cases.

We therefore call for a more compassionate view of the additional mental health impact as part of the appraisal system for acceptance to the SCM award category to be used by IBCA to assess individuals who opt to apply for this additional award. Evidence such as long-term use of antidepressants, counselling for the impact of infected blood and the consequences and suicide ideation should be accepted as proof of additional harm.

We asked our members for their views and experiences in our survey and 108 people gave examples of mental health impact, using the free text format.

The comments from our members reiterated the very different approach and attitude to mental health in the 1970s, 80s and 90s. Many noted that there was a lack of mental health support, as well as a reluctance from many people to talk openly about their feelings. Respondents pointed out that raising mental health problems with their GP would mean that it was recorded on their notes and risked jeopardising future career progression or could count against them when applying for a new job. Comments pointed out that there was stigma attached to seeking help for mental health conditions.

Considering the impact of living with a bleeding disorder, viral infection, impact of medication and the time spent at hospital appointments, many people were acutely aware that the added time needed to seek professional support for mental health issues was just not acceptable to employers. Therefore, even if people were offered support, many declined this and battled on with underlying issues unresolved or manifesting in other forms.

Quotes:

'I'm not sure how to cover those who have struggled without seeking help in any way but have underlying depression and suicidal thoughts.'

'Evidence of long-term counselling, but as counselling was not readily available or offered, evidence recorded in medical notes by haemophilia centres should also be considered.'

'We came from an era where you basically got on with it regardless of how you felt mentally, it wasn't really a recognised condition back in the day, unless you were a persistent self-harmer or were a danger to other people.'

As suggested, we think that medical notes from haemophilia centres and GP records should also be considered within IBCA's SCM appraisal as well as testimonials from individuals and families. The criteria of what they could be is listed within section (V) referenced earlier on the policy paper: (before it was withdrawn in Feb 2025)

Quote:

'Medical record support. Psychologist visits. Other behavioural changes would be evidenced by job loss/suspension/lengthy absence, relationship breakdowns.'

We also believe that there should be a separate award created for infected people in the acute hepatitis C category and those infected with hepatitis B (acute or chronic) who have and can demonstrate considerable mental injury above that compensated for within the core route for this category.

During the infection phase and in the decades afterwards many of these people watched friends die and become seriously ill, with little way of knowing at the time if they would be next. This level of anxiety in some cases prevented them following up on medical care, damaged relationships and families and paralysed their continuation of 'normal life'. The degree of evidenced physical injury does not always directly corelate to the mental health impact for individuals, and this should be recognised, especially for this category of people. Those with evidence of any of the following: prescribed long term anti-depressants, counselling for the impact of infected blood and suicide ideation should be assessed for an additional mental health impact award.

We believe there should be recognition of additional mental health impact to the affected and we will make reference to this in section 6 Supplementary Awards for Affected People.

2***. 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?

As we stated in our submissions to the inquiry in May 2025, we agreed with the position of Dr Sarah Helps, Consultant Clinical Psychologist and Systemic Psychotherapist and at the time of writing Interim Professional Lead of the Infected Blood Psychological Service (IPBS).

She wrote that:

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

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

Those within this category who, due to ongoing severe mental health conditions, are no longer able to work should be able to submit evidence from a qualified mental health professional not exclusively consultant psychiatrist. Very severely affected people may not necessarily be under the care of a consultant.

Section 3 - Recognition of Harm caused by Interferon Treatment

1. ***Do you think there are short term side-effects (lasting less than 2 years) of interferon treatment that we have not taken into account in this proposal?***

As a reminder, Level 2B suggests two extra years of higher financial loss and one extra year of low-level care (16.5 hours per week) compared to Level 2. The types

> ***of short-term side effects caused by interferon include: chronic fatigue, headaches, and insomnia.***

We welcome the opportunity to examine the impact of interferon and associated therapies.

Some of the side effects are listed within the proposal taken from the NICE guidance on interferon and referenced by the Technical Expert Group.

However, consideration needs to be taken of the variation on types of interferon including pegylated and the impact of taking ribavirin alongside interferon. See answer to Q2.

We will address the concept of banding at the end of this section and appropriate awards. We accept the acknowledgement that this therapy often required higher levels of care during the administration phase and that additional care award would reflect that. This would need to be repeated for all rounds of interferon and/or dual therapy with ribavirin.

2. ***If you answered yes to question one, 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.***

Looking at the British National Formulary (BNF) for ribavirin there are many side effects which do not seem to have been considered. As many people had this in combination with interferon it would be remiss not to consider this document: Ribavirin | Drugs | BNF | NICE

We are concerned that the proposal does not appear to recognise the huge volume of evidence around long-term side effects that were presented to the Infected Blood Inquiry in evidence from those infected who were treated with interferon and ribavirin. There was also significant amounts of evidence from those who cared for them. We are also surprised that TEG does not appear to have consulted as widely as it might have done to look at the clinical evidence available.

For example, here are some of the common or very common side effects listed in the BNF but not specially described by TEG in the proposal document.

> *Anaemia; anxiety; arrhythmias; arthritis; behaviour abnormal; chest pain; concentration impaired; cough; dizziness; drowsiness; dry mouth; dysphagia; dyspnoea; ear pain; eye disorders; eye inflammation; eye pain haemorrhage; hyperthyroidism; hypotension; hypothyroidism; increased risk of infection; lymphadenopathy; memory loss; mood altered; nasal congestion; neutropenia; oral disorders; pain; palpitations; peripheral oedema; photosensitivity reaction; respiratory disorders; sensation abnormal; sexual dysfunction; skin reactions; sweat changes; syncope; thirst; throat pain; thrombocytopenia; tinnitus; tremor; vertigo; vision disorders; vomiting;*

There are additional side effects listed as rare and uncommon in the BNF.

Some people also had to endure other treatments such as Telaprivir which used in combination with pegylated interferon to try to eradicate long standing hepatitis C phenotype 1 infection.

One member described being on this combination:

‘The side effects [of Telaprivir and Inteferon] were so bad that I could only be given it after attending sessions to test whether or not my body was capable of standing the treatment, I had to sign a consent/waiver form, and I had to tell my employer. This was mainly because the symptoms included irrational bad temper, lapses of judgement, lack of concentration and suicidal feelings.’

They go on to describe the long term impacts:

‘To this day I suffer from the eczema, have to wear flight socks and apply ointment daily, and have had three procedures to remove/block varicose veins. The mental issues have abated somewhat but have never gone, and after the treatment (which was successful), to the great relief of my long-suffering employer, I handed in my notice having finally exhausted my previously enormous reserves of energy and ambition… I blame the Telaprivir treatment for the many medical issues I’ve encountered since retiring.’

This reflects the experience of people taking this dual therapy as it was anecdotally reported as being much harder to tolerate than interferon mono therapy. However, this may also be attributed to an accumulation or exacerbation of side effects from previous rounds of mono therapy as many on dual therapy had already undergone one if not more rounds of mono therapy. We were not able to find clinical study data to examine the lived experience of side effects of multiple rounds of mono interferon and therapy and/or ribavirin dual therapy or other combination therapies. This does not mean it doesn’t exist, but it does place greater import on the words of those directly impacted who gave evidence to the Infected Blood Inquiry.

Whether the impact of adding in ribavirin or accumulated or exacerbating side effects, the toll that numerous rounds of treatment took on many people was almost intolerable.

The inquiry’s expert report on hepatitis stated that ‘*the side effects were so bad this was a barrier to people accepting treatment’.*

The devastating effects on their lives when undergoing the treatment were sometimes far worse than the impact of living with hepatitis C in the long term.

The following quotes from our members illustrate the horrific impact of multiple rounds of treatment and the variety of conditions which resulted from it:

‘I had interferon three times altogether, for about 6 months a time. Side effects at the time were very hard to bear. Since I also had HCV for about 30 years it is not easy to tell which of my current symptoms are due to Interferon. I would not be surprised if some of the brain fog, bouts of low mood, low energy levels, skin issues, were cause by previous Interferon treatment.’

‘I had four treatments of interferon and then interferon and ribavirin mix! Each one worse than the last! Compensation should reflect every treatment, not just if you were treated with this debilitating, exhausting, painful and suicidal medicine that it was our privilege to endure!’

3. Do you think there are long term side-effects (lasting more than 2 years) of interferon treatment that are not fully covered by the proposed Severe Health Condition award?

We strongly believe there are long term side effects.

The fact that there was no clinical evidence available to demonstrate the long-term side effects and impact speaks more to the fact that the long-term impact of these treatment has been overlooked. The lack of clinical data does not mean that long-term side effects do not exist. Most of the studies looking at the longer follow up to these drugs concentrate on the clinical outcomes such as viral load and liver health and not on the lived experience of the recipients.

Many of our members were outraged and deeply hurt by the conclusion of the TEG regarding lack of evidence of long-term symptoms and its statement that, ‘while depression is a known risk of interferon treatment, studies suggest these symptoms typically resolve quickly once treatment ends’.

This does not reflect the lived experience of many infected and affected family members.

Thanks to the hard work of the inquiry and the generosity and bravery of the community to relive their experiences, we have numerous accounts of peoples’ experience of interferon, the impact on them, their work, family life and their ability to lead a normal life afterwards. We suggest this is the best form of ‘available’ evidence and strongly urge the policy makers and members of the TEG to read the testimonies of the people who endured these treatments and their lasting effects. If that is not sufficient, a retrospective observational study of the lived experience of these patients may plug a clinical evidence gap.

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.

4.*If you answered yes to question one, 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.*

We and the community find it insufferable to have to repeat this evidence. However, once again we are grateful to the community for their generosity and resilience in complying with another request for evidence. We submit a small selection of reflections on the long-term side effects of interferon:

We will also provide a list of referenced witness statements from the inquiry.

> Quotes and links to evidence:
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> *‘My 4th and final treatment which was one of the last 11 month treatments before the new regime was introduced was way beyond horrendous. I have not been able to work since, I have been stressed to the point of requiring medical treatment. I have not slept*

> *more than a few hours consecutively for the past 13 years and the suicidal feelings I was warned about during the interferon treatment have never left. The long term affects of this treatment have never been acknowledged or compensated. Given my time again I would never put myself and my wife through this.'*
>
> *'I have given IBCA my evidence of the long term impacts left by two years of interferon injection, depression, feelings of life not worth living, brain fog, skin problems, compromised immune system, my depression started with interferon and I have tried taking my life on two occasions and will battle depression for the rest of my life, it's all a matter of record and as yet hasn't been addressed in the compensation framework.'*
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> *'I was on interferon along with ribavirin for almost two years, the side effects of these two drugs were horrendous, I went from being a mild-mannered person to someone with very bad depression, terrible mood swings and anger issues, I still suffer from these conditions to this day.'*
>
> *'I believe the majority of my ongoing health issues relate to the interferon/ribavirin treatment. If I had my time again, I would never agree to taking it. It's hard to separate fatigue from HCV and interferon but the cognitive impairment, ongoing severe fatigue, behavioural changes such as panic attacks and anger only started during treatment and most have never improved. My employment was also only impacted once I undertook treatment. My health significantly declined during and after treatment even though I cleared HCV. It is outrageous that experts assert that there are no long-term effects.'*
>
> *'I changed dramatically after first interferon treatment (didn't work) and was made far worse after the second interferon + ribavirin. The biggest changes were as follows:-1 became very short tempered whereas prior was very mild, laid-back personality. 2/ became anxious about anything out of the ordinary. I would avoid where possible going to new places or meeting new people. Prior, I was very adventurous and loved meeting people. 3/ I couldn't go to busy or crowded places after treatment. This altered my job as limited my ability to travel on rush hour trains so mostly worked from home. To this day I will try to avoid crowds so don't go to concerts or busy places. 4/ I regularly go into, what my family call a "shut down mode", where I limit communications. Normally triggered by something as minor as maybe my daughter not taking a bin out. Rather than get angry (point above), I close down. All the above continue every day and has resulted in both my wife and daughter seeking clinical psychological support over recent years due to trying to cope with me.'*

Comments on the suggested Level 2B payment tariff.

We reiterate our comments from THS's May submission to the Infected Blood Inquiry that people who have undergone interferon treatment, irrespective of how many rounds, should be moved onto level 3 payments as per our proposal for the SCM category in section 1 of this consultation. The payments should be initiated from the date of the first treatment and continue. Many of the people may already be on SCM awards and it adds confusion and unnecessary complexity to create yet another level.

We also think there should be a recognition of everyone who had to endure this treatment whether HIV, hepatitis C, co infected, living or deceased. Not only to reflect the suffering of the individuals but the well documented impact on families. We propose that £100,000 is paid to all living and estates of anyone who has been through at least one round of interferon and/or dual therapy.

Again, we urge simplicity to reduce the stress and anxiety of the community, reduce the administrative burden and empower IBCA to make these changes without holding up the payments for the community which desperately wants to try to move on with their lives.

Section 4 - Past Financial Loss and Past Care Awards

1. Where someone chooses to receive Support Scheme payments for life, the Inquiry has proposed that the 25% deduction to past care should be removed (Option 1). The proposal is an alternative where the deduction applied to the past Care award would instead be included in the calculation to determine whether an additional award is paid to their estate upon death (Option 2).

Which proposal do you think creates the fairest balance between compensation for those receiving Support Scheme payments and other claimants?

Our first question is why we are being asked to make a choice between two highly complex calculations that offer imperfect solutions. The Infected Blood Inquiry highlighted this issue and the expectation was that a calculation that provides equity of compensation for all would be put forward.

Asking the community and their advocates to select between two options that disadvantage one section of the population can serve no purpose but to cause harm, division and confusion.

This methodology that has been created by experts for the government. It would be more constructive if those with the expertise within government modify the calculations, taking into consideration the concerns of the inquiry and subsequent feedback from Cabinet Office experts, as reproduced in the consultation document.’

What we need is a system that is fair whether living infected take the core or adjusted route and one that does not disadvantage the estate for losing a loved one early.

We as an organisation representing our whole community have a duty of care to advocate for all of our members so it would be wrong to advocate for an option knowing this will disadvantage a proportion of the community.

2. On calculating past financial loss, we are inviting views on whether people favour the current calculation, which uses an average value for each year, or a calculation that keeps a strict year-by-year approach, with no averaging.

Which approach do you believe to be fairer?

We again refer you to our answer to Section 4, question 1.

We did receive feedback from two respondents who believed that averaging the costs is unfair and preferred the actual costs and losses per year. The fact that we only had two definite responses to this question highlights the complexity of the issue.

We believe a system that is fair for all should be sought. In this instance we’re concerned that government consultation is being used to legitimise flawed options.

Section 5 - Evidence Requirements for Exceptional Loss

1. ***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?***

There may be other options depending upon the individual circumstances of the person applying.

A common concern is from people who were on course for a high-earning profession but whose upward trajectory was halted by infection and/or treatment. This includes people who were studying for or who achieved a qualification for a high earning profession which infection then prevented them from pursuing. To assess this group, an average earnings and progression in that profession could be calculated and could include professions such as accountancy, law, medicine and engineering. Scales of Earning is another measurement which could be used.

There may be evidence kept by HMRC for individuals and businesses that could be used to evidence exceptional earnings. As HMRC can go back at least 20 years to investigate tax evasion we would presume the records are held to that date and beyond. We would expect government to have better knowledge of investigative options, rather than individuals and support groups.

There may be accounts held by Companies House which could prove useful for people running their own business. If the time period precedes what is available on- line then there may be information gained from the National Archives.

Link to the National archives policy osp25-regulation-of-companies-final.pdf

In some circumstances there may be evidence from banks and building societies where earnings were considered for mortgages and possible loan agreements that may be used.

2. ***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 1 (for example if they did not belong to a profession with training and qualifications)?***

IBCA should be given the resources to provide specialist advisory support in this area. An independent employment expert with knowledge of payment models and remuneration should be available to help claimants to find suitable supporting evidence.

Consider an option where the individual is able, if required and requested, to make their case to an IBCA panel, containing at least one independent employment expert. This would allow the applicant to present and explain their evidence. Where complex evidence is involved, an independent panel member with financial expertise may be required.

There should also be consideration of the impact of loss of earnings on personal pension plans. An applicant may have evidence of a company or private pension plan where contributions have been impacted by loss of earnings, caused by infection or treatment.

3. ***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?***

There may be other options depending upon the individual circumstances of the person applying. This has already been addressed to some extent in section 1.

For some professions there are published pay scales where it could be presumed that without the impact of infection the individual would have progressed. Examples of professions with a clearly defined career path are: civil servants, teachers, lecturers and NHS workers.

This may also apply for those working in the medical industry where the fact that they were infected meant they were excluded from their chosen career path.

If there was someone who was at a similar level at the time of the individual’s infection within the same industry or profession they could perhaps be compared to an uninterrupted career progression.

There may be evidence of lost promotion opportunities due to infection. For example, where someone was expected to travel, but could not do so due to some countries’ entry restrictions relating to medical conditions, such as HIV and hepatitis C.

Section 6 - Supplementary Awards for Affected People

1. ***Taking into account the factors set out in this section, including the need to avoid the type of lengthy and intrusive individual assessments that the Inquiry advised were avoided, how would you recommend constructing a form of supplementary award for affected people which would allow for continued, timely delivery of tariff-based compensation awards?***

We suggest a tariff-approach system similar in concept to that which is used for infected individuals for some groups. However, there may be a need, in some circumstances, for IBCA to examine evidence, such as for affected people who have suffered additional psychological harm.

2. Would you support an alternative approach to a supplementary route in place of individual assessment, which would be to pay higher awards to everyone in a specific group, without them having to prove their eligibility beyond belonging to that group? [YES/NO]

Yes.

3. If you do support this approach, which specific groups of affected people do you believe should qualify for a supplementary award on this basis?

a)Those who were under 18 when a parent was infected. This information, as stated in the proposal, would be already available to IBCA.

b) We think there should be a supplementary payment for partners, dependents and or siblings who registered as living in the same household with an infected person whilst they undergoing interferon treatment due to its impact on family life and relationships.

c) We agree with the scenario listed within the consultation document that affected people who have a disability that makes them financially dependent upon an infected person above 18 years for a child or a parent who is dependent on their child for financial support should be eligible for supplementary awards.

d) We think there should also be a route for affected people who suffered additional psychological harm. There should be an exceptional category for those who were psychologically impacted as children.

e) There should be recognition of the detrimental impact on careers that resulted from caring for someone infected.

4. **What pre-existing evidence could IBCA use to determine whether particular applicants belong to these groups?**

a) Age of the child when parent was infected.

b) Date of interferon treatment and family members residing and registered at the same address.

c) The information should be available to IBCA through additional financial care applications.

d) We think there is need for additional evidence to be made available to IBCA, but this must be handled sensitively. Having to provide this evidence can be in itself a significant cause of distress. However the IBSS schemes and IBCA would not hold this information and we feel on balance that this is a necessary step in order for people to receive the compensation they deserve. As set out in Section 2, evidence of counselling, long term anti-depressant use and suicide ideation should be accepted. This could be demonstrated through medical records submitted with their claim.

e) This could be evidenced in a similar way to Exceptional Loss in Section 5.

We want to reiterate that many people have not had access to mental health support or chose not to pursue it due to stigma and secrecy, as outlined in Section 2. This should not be a barrier to recognition and redress for the psychological harm done, which in many cases continues to this day. Indeed, many affected people have told us that psychological harm is being compounded by current delays in the compensation process and uncertainty about when payments will be made.

Section 7 - Unethical Research

1. **Do you agree 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?**

Yes we agree in theory but we do not agree with the cut-off date, which should be later. We know, for example, that there was testing of heat-treated products after 1984 which were deemed to be “safe”, but did not protect people from hepatitis C infection. For example, Armour heat treated product Factorate which was contaminated with HIV and was in use during 1985 & 86 – the product was withdrawn in the Autumn of 1986.

Do you agree that, given the particular circumstances experienced by students at Treloar’s, it is appropriate for them to receive both of the awards?

Yes, we agree

2. **What approach could the Government take to determine an appropriate value of the Unethical Research award?**

Being the subject of unethical research has shaken the bleeding disorder community to its core. To suspect, and then have confirmed, that you – or your loved one – was treated as an object for research, rather than a human being in need of the best and safest treatment, has been devastating. Our survey overwhelmingly found that the current proposed award amount is unacceptable to the infected blood community.

We refer back to the submissions we made to the inquiry in May 2025 where we stated that:

> *An extra £10-15,000 feels extremely low for all the experiences listed as causing the “aggravated distress” described above. The Society contends that people with bleeding disorders treated with concentrated blood products should all be in receipt of additional autonomy route compensation through the supplementary route. We also believe that the uplift for being the subject of research without their consent should be much higher than £10-15,000.*
>
> *The Society also believes that the other aspects mentioned above such as lack of informed consent, inappropriate treatment with concentrated factor products instead of alternatives such as cryoprecipitate and lack of sufficient information about diagnosis, treatment and testing are not included in the core autonomy award or the supplementary autonomy award as described in the regulations. This should be remedied through changes to the supplementary route for the autonomy award to include compensation for this.*

We include a few representative quotes from our most recent survey here, but we urge government to read all the comments attached separately which illustrate very powerfully how much anger and pain unethical research has caused.

Quotes:

‘I am sure it goes without saying there is no amount money that could compensate for the suffering caused by administering untested drugs without prior permission or any knowledge of the drugs by the recipient not mention the secrecy of the administration!’

‘The pharmaceutical companies made significant profits from this practice and valuing testing on children and unauthorised victims at such a paltry amount sets a precedent of low level compensation acceptability.’

‘Can anyone imagine that the medical community tasked with our care would act in such an outrageous manner? The value for this must be exemplary. Anything less than £1m would be derisory given the gravity of what took place.’

Conclusion

This issue goes to the heart of the contaminated blood scandal. It is one of the elements of this disaster which lead Sir Brian Langstaff to conclude that what happened was ‘not an accident’. Widespread evidence that people with bleeding disorders, including children, were targeted by their trusted clinicians to receive treatment at known risk of transmitting deadly viruses because doctors and researchers wanted to see what would happen truly shames our nation. It has taken the suffering of this community to expose this horror and far more must be done to recognise this appalling, unethical behaviour and its terrible consequences.

There is a wide range of views on what would be an appropriate amount to compensate for these actions as shown by the response to our survey, but our respondents were unanimous in the view that £10,000 was not enough. We urge the government to rethink this award and consider the significant and shocking failings that unethical research in bleeding disorder care revealed about the NHS and the state’s failure to protect its citizens. A far higher award must be given.

Additional Points

Loss of potential

Many of our members have spoken to us about the impact of being infected as a child and do not feel the compensation scheme adequately reflects their experience. The impact of infection on their education and life aspirations is largely unrecognised, despite their life-long ramifications. We propose a lump sum Loss of Potential Award for people infected as children (under 18) to address this issue. This should be paid to both the living infected and to estates of those infected as a child.

Through our survey, THS members gave their views on what would be an appropriate amount. Their comments demonstrate why this is such an important issue and we urge government to read them closely and consider an award that truly reflects the appalling suffering described.

Quote:

‘Many of us treated for bleeding disorders were inevitably infected as children and therefore suffered from significant disruption to our childhoods and, critically, our educations. This resulted in absence from school and diminished capacity due to chronic fatigue and brain fogs etc. All else being equal, our infections will have resulted in sub-optimal educational outcomes and therefore career opportunities.’

Equity for hepatitis B

There is a very strong case for acute hepatitis B to be added as a qualifying condition, considering the risk of reactivation. Given that acute hepatitis C qualifies this is something that must be rectified.

We have mentioned within Section 1 about the need for hepatitis B to be included within the new assessments by IBCA for SCM.

We also acknowledge that it is statistically highly probable that all people with bleeding disorders who were regularly treated with blood products were exposed to both hepatitis B and C and therefore were infected with both, at least to acute level. This should be accepted on the balance of probability, rather than look for evidence which, in many cases, is not available. Onerous proof requirements would put additional strain on haemophilia centres and other institutions already struggling with demands for compensation-related evidence.

It is important that those who were also infected with hepatitis D should be acknowledged as coinfected. The serious impact of this combination means they should be compensated at the same level as chronic hepatitis C and be able to apply for the SCM payments.

Exceptional Loss for the death of a loved one

Many of those who have lost loved ones are concerned that the compensation process does not explicitly recognise the death of an infected person. A death as a direct result of the wrongdoing and failures of national institutions and government is not recognised in the current framework.

Quotes:

‘I think the infected estates need to feel that they are being treated equally in the amounts they receive and being listened to.’

‘There is no recognition for those who paid the highest price i.e. lost their lives. There should be some sort of additional compensation to recognise this fact.’

‘Those that are deceased paid the ultimate ‘price’ for this disaster. I feel the compensation for their estates does not reflect this and the suffering they endured.’

Equity between living and estates compensation

In addition to the point above, there is currently an inherent unfairness in the compensation system which pays more to a surviving infected person than to the estate of an infected person who died. This is because of the financial loss calculations which cease at the point of death. An additional disparity has also emerged regarding lump sum payments since the end of the infected blood support schemes on 31 March 2024.

We highlighted our concerns over financial loss calculations in our May 2025 submissions to the Infected Blood Inquiry:

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

7.18.2 If that person died in 1992, their estate would be entitled to £1,023,966.47 in compensation. If that person lived until 2022 the compensation to their estate would be £1,954,626.47. This difference is mainly due to financial loss only being paid to people based on how long they lived. If the person was not married when they died then there is no compensation for financial loss after their death at all.

As mentioned above, there is an additional layer of inequality depending upon whether someone dies before or after the compensation scheme was set up which is captured under Regulation 79.

If someone died prior to 1 April 2024, when the infected blood support schemes ceased to accept new registrations, and had opted for a lump sum, their future financial loss and care amounts stopped at the point of death. However, if a person opted for a lump sum award, accepted it and died after this date, their award would include future financial loss and care until life expectancy (age 86 or 87). The government has clarified that the future financial loss and care payments would not need to be repaid in the latter scenario. This means the beneficiaries of the estate would be paid more than if the person had died before 1 April 2024. This comparison assumes the estates have identical criterion.

This could also impact care payments, as one of our members pointed out:

Quote (via email)

‘This lump sum option seems to apply only to living infected persons who are currently receiving ongoing care support. This support is therefore assumed to continue until the ‘normal life expectancy’ period, that is at least up to state retirement age (65 yrs?). But what if they die before that retirement? Do they have to return an appropriate portion of that lump sum or, as indicated above in the latest Government update, they, (their estate), get all payment as if they had lived until retirement age.

‘If this is so, then it is different to the compensation proposed for those who have already died before IBCA was established. For example, the care compensation allocated to the earlier estates of infected persons, is limited to a maximum of 24 years (for many of the early Haemophiliacs infected, death was way short of retirement age). Why are the two cases different?

‘Secondly, if this also applies to the ‘financial loss’ calculations then the same problem applies because the early deceased infected victims have compensation only up to the date of actual death, not up to an expected date of retirement.’

A fair system needs to be implemented to address this disparity.

Payments to affected bereaved partners and children

In addition to the disparity in financial loss payments between living infected and estates of the deceased, a number of our members have alerted us to another inconsistency. This relates to the proportion of future financial loss paid as part of the affected claim to a deceased person’s spouse. It would appear that there is a reduction of the value of the financial loss award of around 43%. We cannot find any calculations which explain this shortfall.

One of our members has described the disparity in the following way (via email):

‘Financial loss is awarded in two parts - basic financial loss award for infected persons, living or deceased at a set amount (£12,500) and additional financial loss award which calculates a nominal loss of earnings for individuals at a fixed annual tariff for all the years following infection via their NHS treatment with HIV and/or hepatitis (for co-infection this is £18,536 p/a for the years from infection to diagnosis; £29,657 p/a from diagnosis onwards during working years; and £14,828.50 for retirement years).

‘For living infected financial loss is recognised from infection until the national state age of healthy life expectancy (aged 86 for men) as per the Ogden tables. For infected persons who have died prior to the Infected Blood Inquiry this calculation is from the point of infection only until their death, in many cases a few short years later. Where the deceased infected has a spouse, future financial loss from the infected person's death is paid as part of the spouse's affected person claim, but only at 56.25% of the annual tariff figure (£16,682 p/a for working years and £8,341 for retirement years). This is a reduction of the value of future financial loss of 43.75% where there is an eligible spouse. Where the deceased infected was not married this is even greater.’

We do not know on what basis this 56.25% was calculated. But as stated previously it seems a cruel aspect of this compensation scheme that those lives that were thrown into turmoil by the loss of a partner and parent at a young age are disproportionately disadvantaged under the current scheme.

Penalising people for losing their loved ones early is unjust and is something the government needs to address. There needs to be full review of the way estates are compensated to ensure that future changes don’t add to the problem by disadvantaging another group. Tinkering around the edges could deepen the inequalities and we urge the government against any knee-jerk responses which could create more problems, not to mention compound peoples’ anger and distress.

We are mindful that there are many in the community who just want this to be sorted so that they can try to move on with their lives. The government must consider what payments can be made quickly and whether additional sums should follow after further consultation to avoid the process grinding to a halt.

As there have not been questions specifically asked about estates within this public consultation we urge the government to consult with the bereaved on these matters, in a timely, focused manner.

Entailed away estates

We are aware of a number of situations where the estate of the infected deceased is entailed away from family who knew and cared for the infected person. We think consideration should be given as to how this can be addressed as compensation should be for those who have suffered and been infected and affected. Where possible, compensation payments should not be awarded to those who by circumstance find themselves in receipt of compensation for something they never experienced.

Quote:

‘The estates payments are wrong. My brother’s estate is going to his deceased wife’s new husband, where is the justice in that? A stranger who did not know him, did not care for him, did not raise his son as did. It’s so wrong.’

Impact on the haemophilia centres

Haemophilia centres and other organisations, such as the National Haemophilia Database, need more resources to cope with the huge demand from IBCA for compensation-related information. Clinicians and administrative staff must be given more financial support to clear the backlog of requests, which is often delaying compensation claims.

Quote:

'I think the hospitals and treatment centres should have a dedicated member of staff to go through the records and find the appropriate evidence needed for these claims.'

Support and advice for Estate beneficiaries' executors

We would like the government to consider funding additional legal advice and funding for those with complex needs for wills and probates. For example, where there is a need to appoint new executors for a variety of reasons.

There may also need to be support for living executors who are going to be legally responsible for handling large amounts of money on behalf of beneficiaries and may need additional help in carrying out their legal obligations.

'When estates are invited to apply please can we insist that estate executors are given more powers to refer an application to a beneficiary or at best that payment can be made directly to a beneficiary? This ruling with the IBIEPS has caused a headache where my interim payment is having to be paid over several days due to limitations on a personal bank account of £25k per day and when the executor is elderly it means involving more people than is necessary. Assuming my full compensation will be about £1 million this transfer will be unworkable.'