HAEMOPHILIA
SCOTLAND

Response by Haemophilia Scotland to Government Consultation on Proposed changes to the Infected Blood Compensation Scheme October 2025

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The following questions ask for some basic personal information about the respondent. Please refer to the Privacy Notice for information about how personal data will be handled.

1. In what capacity are you responding to this consultation?

✓ I am neither an infected nor affected person, but have an interest in the Infected Blood Inquiry.

About You

2. If you are responding as a person who is or has been infected, please confirm the nature of your infection

✓ Not applicable

3. Please confirm the nature of your interest in the Inquiry (tick all that apply)

✓ Charitable organisation
✓ Campaigner

If applicable - please specify the organisation you are responding on behalf of:

Haemophilia Scotland, a registered Charity in Scotland (SC044298), with its Principal Office at the Eric Liddell Centre, 15 Morningside Road, Edinburgh EH10 4DP. We represent those in Scotland with a bleeding disorder and their families, many of whom have been infected or affected by transmission of infected blood and blood products via the NHS.

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22nd January 2026

Section 1 - The Special Category Mechanism and its equivalents

Questions

Would you like to answer questions on this topic? If you click yes, you will be able to read through the rest of this section before seeing a list of questions at the end

✓ Yes - I would like to answer the questions on this topic

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?

✓ Yes

Please explain reasons for your answer (maximum 20,000 characters)

The Government were wrong to exclude the SCM (Severely Affected Category in Scotland) from the terms of the compensation scheme as this has provided an important aspect of the financial support provided to those infected with Hepatitis C where the chronic assessment (category 1) failed to recognise the severe effect Hepatitis C had on some individuals falling short of liver failure. With the compensation scheme as currently drawn there is too much emphasis placed on liver disease with a failure to take account of other impacts. Those who have benefitted from this payment should have this effect on their daily lives recognised through the compensation scheme.

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?

✓ Yes

Please explain reasons for your answer (maximum 20,000 characters)

It is also important that those who were excluded from the Support Schemes, notably, but not exclusively, those with Hepatitis B are now given the same rights as other infected. This should extend to those who applied to enter the support schemes, but their application was rejected. Through the Inquiry process the inability of the Support Schemes to recognise the needs of those infected with Chronic Hepatitis B has been recognised and in all equity access to the severely affected category should apply to them.

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? Please explain your answer (maximum 20,000 characters).

We support views expressed by the Haemophilia Society that the financial loss element should be set at 80% bringing it to the level that would apply to the cirrhosis category.

This would effectively replicate the position as applies via the Support Schemes. It is difficult to understand why it is proposed to set a different level between what applied in the Support Schemes and what is proposed in terms of compensation. To answer your question, we do not consider this fair.

The intent to make a reduction to 60% following the introduction of effective treatments is neither appropriate nor justifiable. If we look at the position in Scotland, the original treatment for Hepatitis infection was Interferon alone or with a combination of other drugs. Interferon was prescribed for Hepatitis C in Scotland from 1994 to 2016. The fact is that the majority of haemophiliacs did not benefit from "effective treatment". they suffered through toxic and less effective treatment using Interferon, many facing short and long term health problems in consequence.

Do you think the proposal to give people eligible for the award more 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 of this type of care per week?

Yes, in certain circumstances.

Please explain reasons for your answer (maximum 20,000 characters)

On domestic support and ad hoc care six hours per week should cover the majority of circumstances, but there should be provision to extend this where there is an identified higher need. The relevant Regulations should build in a baseline level of support at 6 hours per week with the ability to extend this where there is an identified need for a higher level of support being provided, or required in the future for more than six months.

Section 2 - Severe psychological harm

The next set of questions is on the recognition of severe psychological harm in the Scheme.

Would you like to answer questions on this topic? If you click yes, you will be able to read through the rest of this section before seeing a list of questions at the end.

✓ Yes - I would like to answer the questions on this topic

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?

✓ No

Please explain reasons for your answer (maximum 20,000 characters)

It is unclear what aspects of mental health are covered via the core route. In a document issued on 16th August 2024[1] the Government stated that the injury impact award under the core route covered for past and future physical and mental injury, emotional distress and injury caused by the infection and treatment for it. This is a description of multiple aspects of injury, of which mental health impact is just one part. The sum payable ranges from £10,000 for acute Hepatitis C to £180,000 for co-infection with Hepatitis C or B where there is evidence of decompensated cirrhosis and /or liver transplantation (Hepatitis C) or fatality in the acute period (Hepatitis B). Our conclusion is that it covers a low level of mental health impact which may amount to general distress, anxiety and depression caused by these terrible infections and their aftermath[2]. As this forms a core element of compensation under the tariff-based system, no further justification for the payment is required. It can be assumed everyone suffered some degree of trauma and mental health impact. The value of the award has already been settled in the original Regulations.

The proposed new severe health condition for SCM is also not clearly defined in the consultation. It is intended as a replacement for what in Scotland was defined as severely affected i.e. a person who was unable to work full-time due to physical or mental health impact, had to leave a better paid job, breakdown in relationship due to mental health problems or mental health problems make it difficult to leave home or socialise. This definition could cover a range of conditions, all of which have a

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[1] Policy Paper Government Update on the Infected Blood Compensation Scheme, 16th August 2024.

[2] From Sir Robert Francis' Recommendations to the Government of August 2024 at page 27

significant debilitating effect on claimants. Examples going beyond the core route compensation would include:

- Severe Anxiety characterised by excessive fear and worry and related behavioural disturbances resulting in significant distress or significant impairment of functioning;
- Prolonged periods of depression which can be characterised by feelings of guilt, low self-worth, hopelessness about one's future, including thoughts of dying or suicide;
- Post Traumatic Stress Disorder (PTSD) following exposure to horrific events e.g. life threatening events such as acquiring life threatening disease relating to self or close family members;
- Brain fog resulting in impairment of daily functioning and significant impact on the ability to work;
- Reactivation of past traumas through reliving experiences through the compensation scheme, often associated with mistrust towards or disengagement with the health service;
- Isolation associated with an inability to build relationships.

All these examples would sit within the range of conditions relevant to SCM (Severely Affected Category in Scotland).

The payments made by the Support Schemes should form the basis of any calculation of compensation under this heading. We do not believe that the criteria and assessment process utilised by the EIBSS is the methodology which should apply. We would advocate the system that has applied in Scotland.

The third element mentioned is about Severe Psychiatric disorders rather than psychological care i.e. the medical diagnosis, treatment and management of specific mental health disorders. This has to be based on defined illness criteria and diagnosed by a specialist in psychiatry. We comment further on this in the section below.

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? (maximum 20,000 characters)

The criteria applied currently under the Severe Health Condition Award for Severe Psychiatric Disorder is fundamentally flawed and should be amended. Any report need not be made by a Consultant level Psychiatrist. Any specialist in Psychiatry, e.g. a Specialist Registrar in Psychiatry, is deemed competent to give a reliable assessment and diagnosis of a severe psychiatric disorder and its association with infection. It is only in the most severe cases that a patient would be an inpatient, or the subject of the Mental Health Act compulsory detention. Care may also be provided effectively in the community by appropriately qualified mental health clinicians e.g. Practitioner Psychologists & Community Psychiatric Nurses. It is unclear why a six-month period has been set as a minimum length of treatment. As has been said to the Inquiry, the Government have set the bar too high in prescribing a requirement for:

Consultant-led Secondary care
Inpatient Care
Compulsory detention

The Government should re-consider the criteria for an award under this provision and adopt a more realistic approach. It would be appropriate to note that a diagnosis may exist for variable periods of time, depending on the response to treatment.

The most reliable and effective way of seeking information required would be to ask the treating clinician to certify as part of a pro forma information within their knowledge, skill and experience about the individual.

It should be possible to collate on one form all relevant information certified by the relevant clinician which would also help to minimise the burden felt currently by many medical professionals in sourcing historical data on patients.

Additional Comments

In a psychological treatment setting it is important to respect the confidentiality of clinical records as demands for release could have a significant adverse effect on the relationship between patient and treating clinician. These records held separately from general medical records often contain deeply personal information and requires sensitive handling. Where it is considered necessary to obtain evidence on treatment provided it would avoid unnecessary trauma if a system was implemented to rely on certification by the treating clinician.

Some individuals may have sought non-NHS psychological support, due to a lack of availability in e.g. England until recently. There may be additional practical difficulties in obtaining reports in those circumstances e.g. records not retained or the practitioner requiring a fee for the provision of a report.

Section 3 - Recognition of harm caused by interferon treatment

The next set of questions is on the recognition of harm caused by interferon treatment in the Scheme.

Would you like to answer questions on this topic?

✓ Yes - I would like to answer the questions on this topic

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?

✓ Yes

If you answered yes to the first question, 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 (maximum 20,000 characters).

It should be recognised that the adverse effects of Interferon alone, or prescribed with other medications (not just Ribavirin) had a psychological, medical and physical impact on many recipients of this treatment regime.

The full quote of adverse effects from Interferon treatment as contained in the NICE guidance[3] is:

"Many, but not all, people find interferon alfa therapy very hard to tolerate. After each injection, they may suffer influenza-like symptoms, and up to one-half of all people treated suffer from chronic fatigue, headaches, pyrexia (fever), myalgia (aches and pains), insomnia and/or nausea. About one-quarter suffer hair loss, arthralgia (pain in the joints), rigors, irritability, pruritus (itching), depression, dermatitis and/or decreased appetite".

This does not emphasise the high level of depression suffered by many recipients. Treatment was often associated with an itchy rash, so common that creams and lotions were routinely issued to help reduce the impact. Treatment required patients to take a high fat diet to assist in the absorption of treatment. Many found this difficult.

The side effects mentioned do not reflect the physiological impact of treatment. Patients' had to be monitored closely and common issues faced were anaemia requiring further medical intervention, including transfusion and/or erythropoietin injections; cardiac arrhythmia and hypotension. Reference should also be made to the article by Geoffrey Dusheiko, Side Effects of Alpha Interferon in Chronic Hepatitis C [4] as referenced in the Inquiry documentation.

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[3] National Institute for Care and Excellence (NICE) Interferon alfa (pegylated and non-pegylated) and ribavirin for the treatment of chronic hepatitis C (January 2004 – updated November 2013)

[4] Infected Blood Inquiry Witness Statement WITN3574019_0001

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.

✓ Yes

If you answered yes to the previous question, 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 (maximum 20,000 characters).

Our members have reported to us various long-term effects of interferon. There is a lack of studies on this subject, although we have identified three studies from the USA which link Interferon as having long term effects or exacerbation of other conditions. Examples include on-going fatigue[5], Rheumatoid Arthritis[6], Autoimmune Hypothyroidism[7].

One member commented that “for the expert group to suggest there are no predictable long-term side effects from interferon treatments is an astonishing and horrible insult to the wider community. Lack of clinical evidence/empirical data does not mean these issues do not exist and so to suggest they shouldn't be recognised in compensation awards is frankly a disgraceful statement.”

Another member previously infected with Hepatitis C and now being treated for Hepatocellular Carcinoma has identified that whilst he received a sustained viral response to the infection has been advised by his doctor that he is now suffering from Hepatitis alongside his liver cancer. This shows that there can be significant long-term consequences of Hepatitis infection even when what might be classed as a “cure” has been achieved.

We have had reported to us multiple instances of patients being left with chronic fatigue. of having to have rest periods during daytimes, just to get through a day and to have energy to make it through evenings. Clearly this has an effect on ability to work, be effective in a workplace and also on enjoyment of life and mental health.

From a small sample of our members we have received information on a variety of long-term conditions which have affected them following Interferon treatment. The list includes anxiety, asthma, chronic arthritis, rheumatoid arthritis, severe eczema, depression, loss of concentration, personality disorder, Peripheral neuropathy and fatigue.

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[5] Psych Neuroendocrinology. 2019 Feb;100:276–285

[6] Clinical Rheumatology . 2001;20(4):297-9. doi: 10.1007/pl00011206

[7] Clinical Experimental Rheumatology. 1997 Jul-Aug;15(4):415-9

Additional Comment

We believe that the proposed way forward from the Government does not adequately and fairly recompense those who have received often multiple courses of Interferon treatment and associated side effects. The Government's proposal is to pay a lesser sum than was recommended by the Inquiry in response to the side effects of Interferon and Interferon related treatment. The approach taken is that a new Severity Band at Level 2B award be implemented for those on Level 2 who have received interferon and Interferon related treatment. (The Inquiry proposed uplift to Level 3 or a new Level 2B) The change proposed will have the effect of an uplift from Level 2 in terms of injury award, financial loss award and care award. This fails to recognise that many who underwent Interferon treatment have already been classified at Level 3 and will therefore receive no or limited additional compensation for the adverse effects of Interferon treatment. This is treatment which typically lasts between 6 and 12 months dependent on the genotype and which was often repeated two or three times, or more with significant side effects as identified in our response to an earlier question. We believe it would be much fairer if a fixed payment was received for each course of treatment with Interferon. One figure should be set for periods of planned treatment up to 6 months, with double that payment set for each period of 12 months. Where treatment was started, but stopped for medical or psychological reasons e.g. suicidal or emotional lability, the payment for the relevant period should stand. We believe that the basic level of payment should be £10,000 for six months of treatment and £20,000 for 12 months. These payments should be made as part of the core award to minimise the number of supplementary claims.

Adoption of this approach will ensure that the most severely affected will benefit from the additional payment for the adverse impact of Interferon treatment whether this be in the short or long term. Recipients of Interferon who suffer from any of the conditions listed as eligible for severe health conditions should continue to be entitled to these payments. Those co-infected with HIV should have an entitlement to this payment as the impact relates to their Hepatitis infection treatment.

Section 4 - Past financial loss and past care awards

Would you like to answer questions on this topic? If you click yes, you will be able to read through the rest of this section before seeing a list of questions at the end

✓ Yes - I would like to answer the questions on this topic

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?

✓ Option 1

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?

✓ Averaging

Please explain reasons for your answer (maximum 20,000 characters)

The issue raised with the Inquiry mainly by recognised legal representatives[8] was that the complex calculation introduced to the Compensation (Amendment) Regulations 2025 had the effect of depriving those who opted to receive on-going support scheme payments from receiving the full value of past care payments due to the 25% deduction. That is the issue that needs to be addressed.

The Inquiry expressly recommended removal of the 25% deduction. Option 1 gives effect to that recommendation in a clear and transparent manner. By contrast, Option 2 introduces additional complexity and defers payment of part of an individual's compensation until after death, which is neither equitable nor consistent with the compensatory purpose of the Scheme. Compensation for past care is intended to recognise loss already suffered and should not be contingent on survival or paid only to an estate.

The suggestion that removal of the deduction would disadvantage estates is not clearly substantiated. If any imbalance were identified, it should be addressed directly through estate provisions rather than by maintaining an unjust deduction from living claimants' awards.

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[8] Infected Blood Inquiry Additional Report 9 July 2025 pages 148 – 149

In relation to past financial loss, the averaging approach is fairer and more consistent with the principles underpinning a tariff-based scheme. A strict year-by-year calculation risks arbitrary outcomes driven by the timing of disease progression, treatment availability, or administrative cut-off dates, rather than by the overall economic harm suffered. Averaging smooths these distortions particularly for those infected in childhood or whose condition deteriorated later in life.

Whatever approach is adopted, it must ensure that there is no detriment to those who have had their claims settled i.e. there should be no clawback from those whose claims have already been paid.

Section 5 - Evidence requirements for exceptional loss

The next set of questions is on evidence requirements for exceptional loss.

Would you like to answer questions on this topic?

✓ Yes - I would like to answer the questions on this topic

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? (maximum 20,000 characters)

We cannot see how evidence of a professional qualification is an indicator of earning. There are professions where the level of earning will fall below the UK median salary +5%. How would one translate a professional qualification to a specific and proven level of earnings? This is an entirely inappropriate proxy for actual earnings.

What might be appropriate is where a person is employed in a role where there are published standard salary levels that can be established e.g. in the health service or local authorities, but use of this information may discriminate against others who are not in that position.

The Regulations refer to PAYE earnings. It would, one assumes, be within their existing powers available to the IBCA to source from HMRC relevant income and tax records as proof of earnings without the need for claimants to produce this material. Alternatively past banking records might show regular payments into an account from a named employer which should be sufficient evidence of earnings. Another possible source is pension scheme records of contributions.

For the self-employed relevant accounts for the period may be available from HMRC or an accountant to evidence earnings.

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 the first question (for example if they did not belong to a profession with training and qualifications)? (maximum 20,000 characters)

It is essential that any Exceptional Loss award is underpinned by a common and objective evidential standard. Introducing alternative or proxy forms of evidence risks undermining fairness and consistency between claimants and would sit uneasily with the tariff-based structure of the Scheme.

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? (maximum 20,000 characters)

The passage of time and the historic nature of these claims mean that documentary evidence may no longer be available in some cases. However, exceptional loss awards necessarily require a higher evidential threshold.

Where primary documents are missing, IBCA could consider obtaining corroborative financial evidence from third-party sources, including HMRC income and tax records, National Insurance contribution, accountant-held records, historic banking information evidencing income streams, or pension scheme contribution and payment records.

Section 6 - Supplementary awards for affected people

The next set of questions is on supplementary awards for affected people.

Would you like to answer questions on this topic?

✓ Yes - I would like to answer the questions on this topic

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 [to be] 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? (maximum 20,000 characters).

The 2025 Regulations make very limited provision for supplemental awards for affected people: a supplemental award is only available to bereaved affected people who were financially dependent on an eligible infected person at the time of the latter's death. If eligible, they may be entitled to £5,561 per annum from the point of death to the estimated healthy life expectancy of the deceased (or £2,780.50 per annum for years where the infected person would have been 66 or older).

The evidence which the Inquiry received from people infected and affected makes clear that there were partners, parents, children and siblings who suffered serious (and sometimes lifelong) psychological trauma, with some developing psychiatric disorders such as depression and PTSD. Many took on significant caring responsibilities, often having to give up paid employment to support their infected child, sibling or partner The consequential adverse impacts on health, education and careers must be capable of being recognised through the compensation scheme.

It is disappointing that the Technical Expert Group and Civil Service have not found a way of ensuring that the affected who have suffered additional loss are fully recompensed. From our knowledge the type of impact suffered by the affected include:

- Depression,
- Stress and Anxiety
- PTSD
- More serious mental health and psychological trauma
- Loss of earning through ceasing work to support the infected
- Impact on child development from lack of stable parental support or chaotic home life from the infection

There are no doubt additional areas which will be raised in response to consultation.

It is very clear from evidence to the Inquiry that the affected have suffered adverse effects on their mental health over a prolonged period. These effects include anger, anxiety, complex grief, complex trauma, depression and fear of stigma. We fear that this array of conditions experienced by the affected has not been recognised in drawing up the compensation scheme.

On mental health impact, where this can be shown through certification by a treating practitioner, the same rules as apply to SCM could be applied.

Loss of earning could form a supplementary route under financial loss based on evidenced loss. Mental health impact could be based on a tariff based on condition Impact on children could be linked to a given period e.g. whilst the child was under 18, with a set figure awarded.

In each case the Government would need to take advice on the appropriate level of compensation.

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

If you do support this approach, which specific groups of affected people do you believe should qualify for a supplementary award on this basis? (maximum 20,000 characters)

We would suggest that a fixed tariff could be applied in the case of mental health impact. Also impact on child development up to the age of 18 where one or more parents infected.

What pre-existing evidence could IBCA use to determine whether particular applicants belong to these groups? (maximum 20,000 characters)

In cases involving financial loss historical information on earning and employment would be appropriate from sources such as those mentioned in Section 5 on Exceptional Loss.

A set tariff for the impact on childhood would be appropriate thus avoiding the need for new evidence. Records of birth, marriage, civil partnership and death would provide the appropriate information.

Section 7 - Unethical Research

The next set of questions is on unethical research.

Would you like to answer questions on this topic? If you click yes, you will be able to read through the rest of this section before seeing a list of questions at the end

✓ Yes - I would like to answer the questions on this topic

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, but

Please explain reasons for your answer (maximum 20,000 characters)

We believe that all infected people who received treatment for a bleeding disorder during a specified period should be eligible for an unethical research award without needing to produce further evidence. We say this because of the difficulty in sourcing evidence relating to research studies and because many in the community believe the Government's current list to be inaccurate. Eligibility should not be based on specific medical institutions. We also disagree as to the eligible period. We raised this in response to the previous consultation on this issue but our views were ignored. What we said then, and remains valid, is that some of the research took place after 1984 and that unethical research at Treloars took place in the early 1970's. We quote below our previous response in relation to the end date:

In Volume 4 of the IBI report at page 304 it is stated "Thus, even in in the 1990s – at a point in time at which lessons which should have been learned from the transmission of HIV and Hepatitis B and C, and the fundamental importance of providing clear and unequivocal information about risks of viral transmission to participants in research should have been at the forefront of the design of clinical trials, and that safety was paramount – children were being recruited to clinical trials being organised by SNBTS[9] without proper information about the risks being provided. This was unethical and wrong".

One of our members has referred us to his witness statement to the Inquiry which refers to a study undertaken by Professor Ludlum and Dr Hanley published in July 1996 on an "Investigation of chronic hepatitis C infection with haemophilia: assessment of invasive and non-invasive methods". An abstract from the research report can be found at:

https://onlinelibrary.wiley.com/doi/10.1046/j.1365-2141.1996.6192064.x

The member says he was unaware that an endoscopy he underwent was part of a trial for which no consent was recorded in his medical records. He does not recall being asked to participate in any research. The study in 1994/1995 involved a cohort of 87

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[9] Scottish National Blood Transfusion Service

patients at the Royal Infirmary of Edinburgh long after the cut-off date proposed of 1984”.

From previous freedom of information requests to the Medical Research Council, it is known that research grants relating to the following clinicians/hospitals were undertaken. We cannot say that these research studies were unethical, but if individuals who had been subject to this research claimed it was unethical, they should not be denied the right to compensation:

ID	**Institution**	**Clinician**	**Start Date**
G8514756/1	Edinburgh University	Ludlum	01/08/1986
G8719755/1	Oxfordshire Health Authority	Rizza	11/07/1988
G813838/1	Cardiff University	Bloom	12/01/1989
G8718714/1	South Birmingham PCT	Hill	31/01/1992
G8902835/1	Edinburgh University	Ludlum	01/08/1993

We suggest that the Cabinet Office make further enquiries of these research studies. Details are provided in WITN1146038 on the Inquiry website.

It should also be remembered that however comprehensive the work of the IBI, it could not realistically record every incident of unethical research. **Based on the information we have presented, we believe that the cut-off date for eligibility should be no sooner than 1996.**

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

Please explain reasons for your answer (maximum 20,000 characters)

The pupils of Treloars attended the school to receive specialist care for haemophilia in a trusted setting. That trust was utterly destroyed by the staff of the school. Some 89 pupils of the school have died as a result of unethical and unauthorised medical experimentation and research. So many young boys have lost their lives as a consequence. It is the most horrifying aspect of the consequence of the infected blood disaster. The survivors and their families are more than deserving of compensation which includes the two elements. Whether the sums suggested by the Government is adequate is very debateable.

What approach could the Government take to determine an appropriate value of the Unethical Research award? (Maximum 20,000 characters)

As we understand it the Government are not proposing any change to the sums involved than was originally suggested despite being invited by the Infected Blood Inquiry to do so. They are inviting suggestions. We note the view expressed by Government that the compensation on this heading does not take account of the psychological and physical impacts of research or treatment which is already covered by the autonomy award.

We are aware that many within our community believe that a significantly higher level of compensation is justified, given the serious and enduring harm caused by their unknowing participation in research programmes and tests being performed without consent. We wholeheartedly support these sentiments and look to Government to set a more realistic figure.

Our view is that the impact of unethical research is such that it should equate as a minimum to the level which is provided for under the autonomy award for Hepatitis B or C infection at Level 2 or 3 i.e. £40,000. This should be the baseline for simple unethical research. For Treloars pupils this should amount to a total of twice this sum i.e. £80,000 reflecting the particular circumstances where parents and pupils alike put their trust in the medical profession only to see their young son’s lives destroyed at an early date.

Sir Brian in his Additional Report set a test of what might accord more closely with the general public’s sense of justice and fairness in respect of an individual being subject to research without informed consent. We believe that the general public will have sympathy with what we propose. It will also quell some of the extremely strong feeling within the infected community that what has been proposed by Sir Robert and the Government is derisory and fails to recognise the true cost of the injury suffered.

We also feel that, if possible, this element of award should be taken out of the supplementary route in the next set of Regulations and be made a core element to avoid individuals having to go through the supplementary route for this item.

Section 8 - Additional issues

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? (maximum 20,000 characters).

✓ Yes

Format of the Consultation

The consultation document is very complex and would have benefitted greatly from lay summaries and presentation of the proposals on which views are sought. Although videos were created to be accessible and to support people's understanding of the document, they do not contain any of the important details of the suggested changes. This has been a clear barrier to accessing helpful feedback from the community. Furthermore, there is an expectation that people have detailed knowledge of previous criteria (e.g. SCMs and how these were assessed in different regions of the UK) or even an awareness of how to access that information. Equally the technical nature of some of the sections is impregnable. Links or basic summaries would have been helpful and would have supported people's ability to comment in an informed way.

The decision not to publish as routine the responses submitted is unhelpful and lacks transparency. The need to protect confidential information, including personal experiences, is understood, but the Government should have looked to how the Infected Blood Inquiry successfully took evidence from a large number of individuals without breaching confidentiality. We sincerely hope that the Government will see fit to publish summaries of all the replies received to help inform understanding of the important issues raised.

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