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Statement No.: Fifth WITN6392288

Exhibits: WITN6392289 – WITN6392300

INFECTED BLOOD INQUIRY

WITN6392290

The Haemophilia Society

Submission on the proposed Infected Blood Compensation Scheme

A summary of issues, concerns and anomalies arising from the scheme from the Haemophilia Society and its members

June 2024

Registered charity no. 288260 Registered charity in Scotland No. SC039732

Contents

Introduction

The publication of the government's Infected Blood Compensation Scheme could have been a crowning moment in an historic period for the contaminated blood community.

Instead, the scheme's failure to recognise fairly the suffering caused and its attempt to remove existing ex gratia support has resulted in unprecedented anger, frustration and fear from our members.

Those infected and affected by contaminated blood and blood products had less than 24 hours to digest the enormity of the Infected Blood Inquiry's final report before the government published its compensation scheme.

As the details of the scheme began to sink in, the feelings of elation and vindication which had resulted from inquiry's findings quickly evaporated, to be replaced by more familiar emotions of suspicion and uncertainty.

It had happened again. The government had created a major scheme without one word of consultation with the people it was designed to support. The blinkered way in which this scheme was built is shocking.

The impact of the publication of the compensation scheme on 21 May has been immense. The Haemophilia Society's small team has been overwhelmed with phone calls and emails as our members grapple with what the scheme means for them. We experienced a 300% increase in telephone calls in the weeks following the announcement, many of them tearful and confused. Still more enquiries followed, demanding complex answers which, for the most part, we were ill-equipped to provide. We were inundated with questions, to which we had very few answers.

Once again, our community is dependent on the charities working in this area with limited resources, as well as the dedicated unpaid campaigners who courageously support others while privately dealing with their personal trauma.

Our members are desperate for information. More than 300 people crowded onto a webinar which was originally designed to discuss the report's findings but was dominated by questions about compensation.

Comments on social media threatened to turn ugly, uncertainty once again leading to division and distrust. The psychological damage caused by the proposals in this scheme and the questions resulting from them has been significant. In England it is made worse by the lack of bespoke support for the contaminated blood community.

Our members are emotionally spent and are struggling to deal with the issues thrown up by this compensation scheme. Following the inquiry's final report, many people are dealing with feelings of acute grief and loss as they attempt to navigate this, hopefully, final stage of justice without cherished loved ones.

Time is clearly of the essence, but this does not mean that engagement and vital detail can be overlooked. Our plea to the Cabinet Office, Sir Robert Francis, David Foley and the staff of the Infected Blood Compensation Authority (IBCA), who will administer this scheme, is to listen. The needs of our community need to be considered carefully.

Every member of IBCA staff needs to understand the issues and sensitivities surrounding the implementation of the scheme. We again offer our support in assisting in this and ask those who run the authority to ensure this happens.

Our submission contains thoughtful, personal feedback on the compensation scheme from around 1,000 members. The central issues are about fairness, about ensuring everyone's loss and injury is recognised and about government honouring previous financial commitments.

IBCA now carries the responsibility of delivering fair, generous and swift compensation to a community which has waited far too long to receive it. We offer you our help, through the views of our members, in ensuring this is finally achieved.

Method

In developing this written input to the engagement exercise we have relied on the hundreds of phone calls, emails and letters we have received from our members as well as an online survey that was conducted from 20-26 June.

The survey was sent to Haemophilia Society members via email. There were 893 responses which included 342 infected people, 496 affected people and 55 people who were both infected and affected. Not all questions were answered by all respondents. We have included some questions and quotes in our submission below. The full data including all comments have been provided to IBCA.

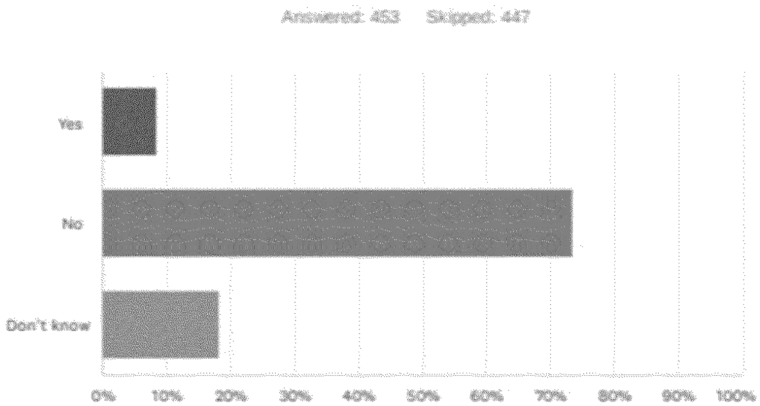
Support Payments

We received many calls and emails from people fearful and anxious about their financial security and that of their family. The majority want these schemes to continue.

Quote from survey:

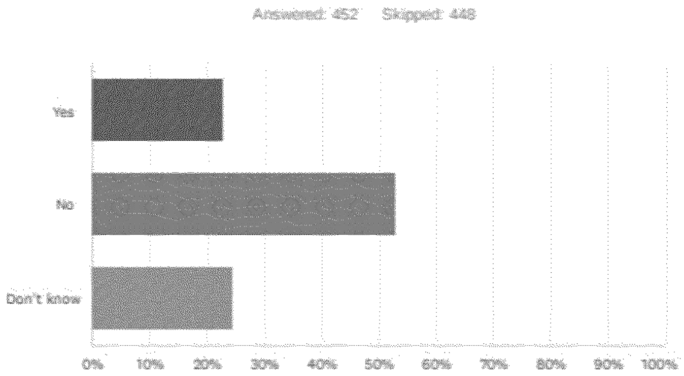
"The illustrative figures provided... represent a fraction in support payments I would receive if living for another 30 years - which is very possible."

Q5 - There was an expectation that support schemes would continue for life. Under the current proposals the support schemes will stop at the end of March 2025 to be replaced by compensation. Compensation will be paid as either a lump sum or periodical payments. Based on your current knowledge and expectations, are you happy with the proposed compenation scheme?

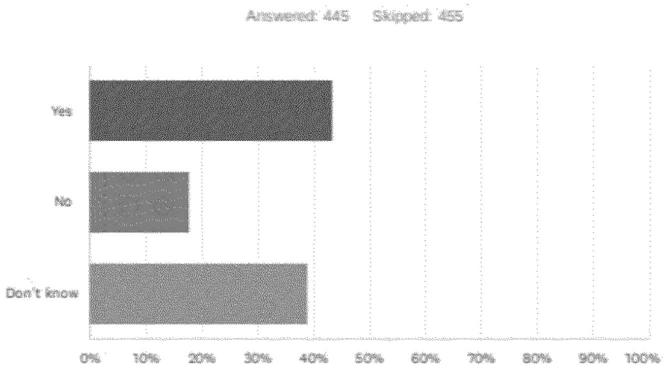


Even when reassured that they would not be worse off under the new scheme people still wanted the support schemes to remain.

Q7 - The Government says it will put in safeguards so no one will be worse off under the new scheme. If you would be no worse off under the new compensation scheme, would you accept the ending of the current support schemes?



Q11 - If you currently receive support payments and you were offered an enhanced lump sum which replaced the support payments, would you consider taking it?



Lump sum vs. ongoing support

Some within the community would welcome the opportunity to be in charge of their own financial future.

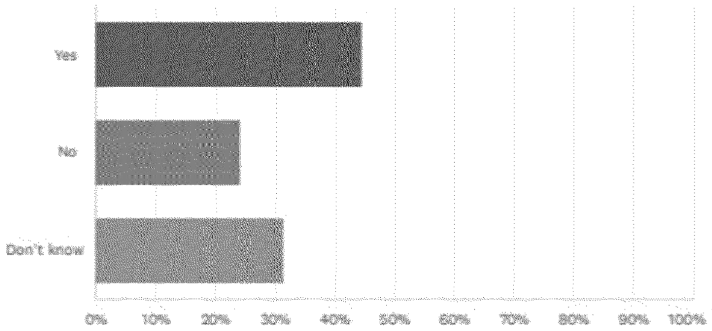
Quote from survey:

"Providing the lump sum accurately reflected compensation for suffering and truly would make me no worse off, then I would be relatively content."

But there is a large proportion of the community, as demonstrated by the answer to our survey questions, that would want support schemes to continue even if the amounts truly reflected both past loss and future financial need. For some people no amount of compensation will make the removal of the support schemes acceptable.

Q8 - Would any level of compensation payment (for example if you would receive twice as much) be sufficient for you to accept the removal of the support schemes?

Answered: 450 Skipped: 450



Some have expressed anxiety over the burden of managing a large lump sum and the stress of ensuring this will provide financial security for life, as well as the risk of falling foul of fraudulent schemes and scams.

Quote from survey:

"Switching support payments for a lump sum, for people who are wholly reliant on that income, would add the risk and cost of managing that."

It is clear that a substantial minority of people would not accept the removal of the support schemes under any circumstances and expect the support payments to be maintained in full, in addition to compensation from IBCA. We remind IBCA that in evidence to the Infected Blood Inquiry in May 2021 the then Health Secretary Matt Hancock said under oath: "I would absolutely give a commitment to anybody receiving a payment, any of the beneficiaries infected or affected, that I would expect that to continue for their lifetime."

The proposals as currently set out will deduct future paid or expected support payments from people's total compensation. This will leave some people receiving little or no compensation at all. This is completely unacceptable to our members and to the Haemophilia Society.

This is contrary to the wishes of both Sir Robert Francis' compensation report and the Infected Blood Inquiry. The recommendations of the Infected Blood Inquiry (recommendation 13) allowed for future support payments to be deducted from only part of the compensation award, not the full amount as currently proposed.

Taxation

Questions over issues of taxation have been raised by many. The proposed compensation scheme contains the following pledge:

"Compensation payments made under the Scheme will be exempt from income tax, capital gains tax and inheritance tax. This is in line with tax exemptions for the first and second interim payments."

However other issues have been raised which need more scrutiny and clarification.

- How would taxation on interest and earnings from any lump sum be considered when looking at how much support someone would need in the future considering the sums would not be able to have been invested in a tax-free ISA as an example?
- Would this trigger the need for people to submit self-assessment tax returns each year with income from a lump sum?

Quote from a member via email:

"Please also remember that many survivors are elderly and may not have computers or even on-line access so will be unable to complete the necessary forms!"

Impact of proper financial planning

If we look at scenarios provided in the supplementary documents that comprise appendix 2, with the provision of proper financial advice, people will be more able to secure a stable financial future. Many parts of the community have never had the need to secure a financial advisor. THS believes IBCA has a responsibility to provide independent, regulated financial advice and guidance as part of the compensations scheme.

Quote from survey:

"Financial advice is essential. Finding a competent and trusted financial advisor who fully understands our specific needs is quite daunting. Free one-to-one financial advice should be provided."

Access to independent advice regulated by the Financial Conduct Authority will help individuals and families ensure they receive best potential returns on investments resulting from lump sums. It will also help to protect the infected blood community from unscrupulous operators intent on defrauding them of their compensation payments.

Scams and Fraud

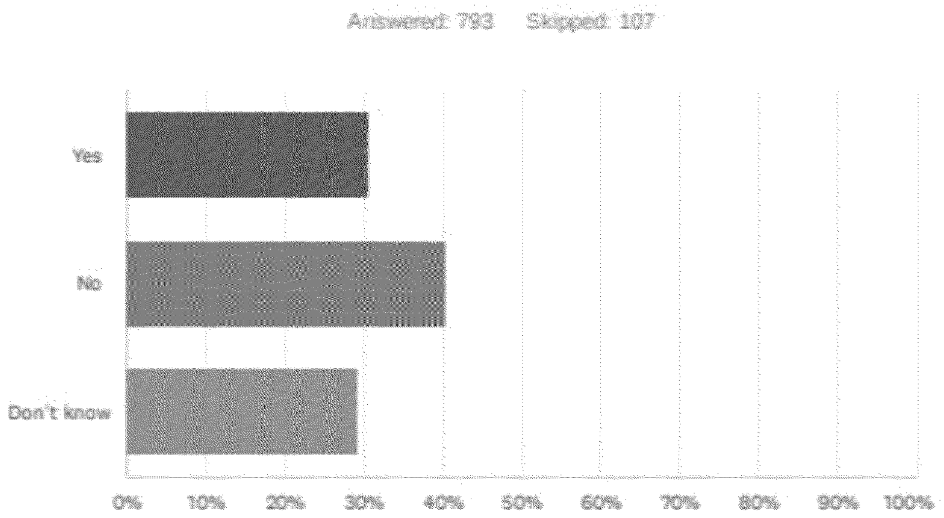
The publication of the Infected Blood Inquiry and subsequent announcements from the government have generated much media interest. Many people have spoken publicly about their connection with the contaminated blood scandal and numerous online support groups have been established on social media. We are concerned that our community is at risk of being targeted by scammers and fraudsters now that it is widely known they are to receive compensation.

Having taken professional advice on security, we believe there to be a real threat not only from local fraudulent activities but also from organised crime gangs and state sponsored targeted attacks, given the amount of money involved. We therefore urge the government to make adequate provision to inform and protect, where possible, the recipients of compensation.

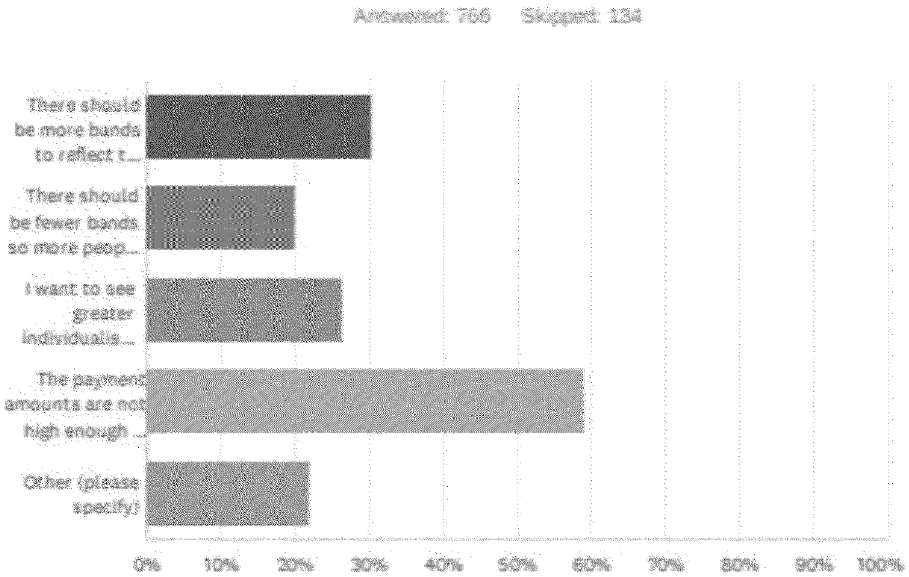
Categorisation of hepatitis C

We do not believe the categorisation of the impact of hepatitis C adequately covers the complexity and severity of this condition. The hepatitis C 'chronic' banding does not go far enough to capture the range of experiences people have been through.

Q13 - Under the proposed IBCA scheme the government allocates payments depending on the severity and length of impact of hepatitis B and C. Hepatitis B Acute (where the infection resulted in a fatality in the acute period) Hepatitis C Acute or B - Decompensated cirrhosis and or/ liver cancer or liver transplantation. In your opinion does this adequately represent their range of experiences?



Q14 - If changes were to be made to these bandings which of the following areas should be reflected in payments? (tick all that apply)



Answer choices	Responses
There should be more bands to reflect the wide range of impacts of these viruses	**30.29%** 232
There should be fewer bands so more people receive the same compensation amount	**19.97%** 153
I want to see greater individualisation of payment amounts to reflect my personal experience	**26.37%** 202
The payment amounts are not high enough to compensate me for my loss and suffering	**59.01%** 452
Other	**22.06%** 169

Related conditions

The range of conditions that are directly related to infection by hepatitis C or the subsequent treatments to eradicate the virus, are recognised by the infected blood support schemes and the inquiry-appointed hepatitis C expert group. These conditions have not been included in this scheme.

From the England Infected Blood Support Scheme website:

[illegible]

- **an autoimmune disease which was due to, or worsened by, interferon treatment. This includes coombes positive haemolytic anaemia, idiopathic fibrosing alveolitis of the lung and rheumatoid arthritis**
- **sporadic porphyria cutanea tarda (causing photosensitivity with blistering)**
- **immune thrombocytopenic purpura, if autoimmune with antiplatelet antibodies**
- **type 2 or 3 mixed cryoglobulinemia, if accompanied by cerebral vasculitis, dermal vasculitis or peripheral neuropathy with neuropathic pain**
- **been affected in performing your daily duties due to the infection or the treatment**

Also, the inquiry's expert group on hepatitis had this to say about associated conditions in their section on rare potential complications associated with chronic hepatitis B and C viruses:

"Cryoglobulins are abnormal immune proteins. Both HCV and HBV can lead to production of cryoglobulins. When present in the blood they can cause a variety of problems, such as skin rash, joint pains or kidney damage. Chronic infection with hepatitis C is associated with a small increased risk of lymphoma."

We are aware of at least one case of someone developing non-Hodgkin lymphoma which has been directly attributed. Other people with conditions on this list who have contacted us are extremely anxious that their secondary conditions and the long-lasting effects caused by infection are not being taken into consideration. For example, the lasting effects of peripheral nerve damage than can occur from cryoglobulinemia.

The same expert report also said:

"A rare complication of HCV infection is a condition called essential cryoglobulinemia which is associated with a skin rash and peripheral nerve damage, and loss of sensation in the fingers. Cryoglobulinemia resolves once the infection is cured, but damage to the nerves may not improve."

The impact of these secondary conditions warrants a higher banding to reflect the pain and long-term suffering these people have endured, and we urge you to review this banding to increase the injury award.

Special Category Mechanism (SCM)

The Special Category Mechanism (SCM) in England, and equivalents in other parts of the UK, is utilised by the support schemes to identify those people who have suffered a level of impact which has affected peoples' ability to work and carry out normal daily living. This has been overlooked by the compensation framework.

The England Infected Blood Support Scheme makes higher payments to people through the SCM if their "infection, its treatment or associated conditions, has a long-term negative impact on[their] ability to carry out daily activities" or their "condition has worsened, but is not stage 2."

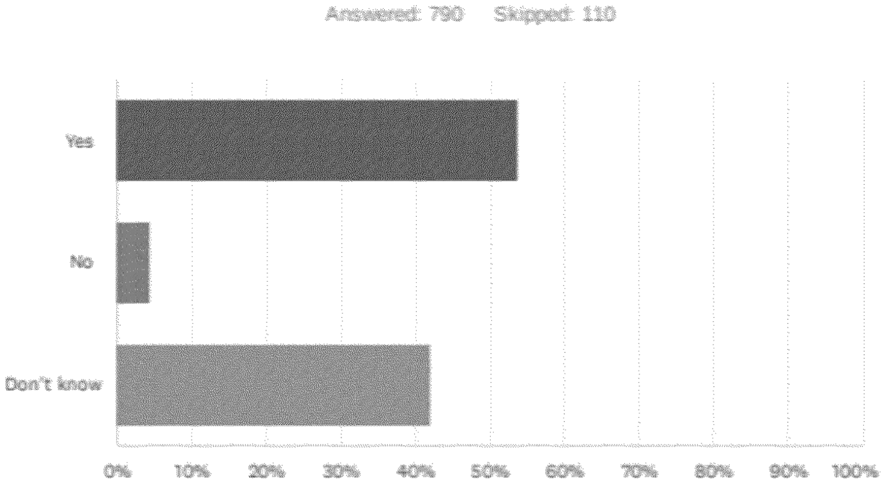
Clinicians have already acknowledged and evidenced the clinical need in line with current schemes. The includes the psychological impact and well documented issues such as chronic fatigue and "brain fog".

Quote from an email received 30 May:

"My issue is, if the term "chronic" only refers to the length of time someone was infected rather than for any medical reasons, yet the EIBSS has agreed by granting my SCM status that I have additional issues over and above Stage 1 that equate in value to Stage 2, why does the upper illustrative value of "chronic" not overlap with the lower "cirrhosis" level on the IBCS policy in the IBCS award structure? "

There should be recognition of the people who have been reviewed and considered eligible due to the impact of their condition and appropriate levels of funding incorporated into any scheme.

Q15 - Would you like to see a banding which includes additional impact on day-to-day life for example the Special Category Mechanism (SCM) used by the support schemes?

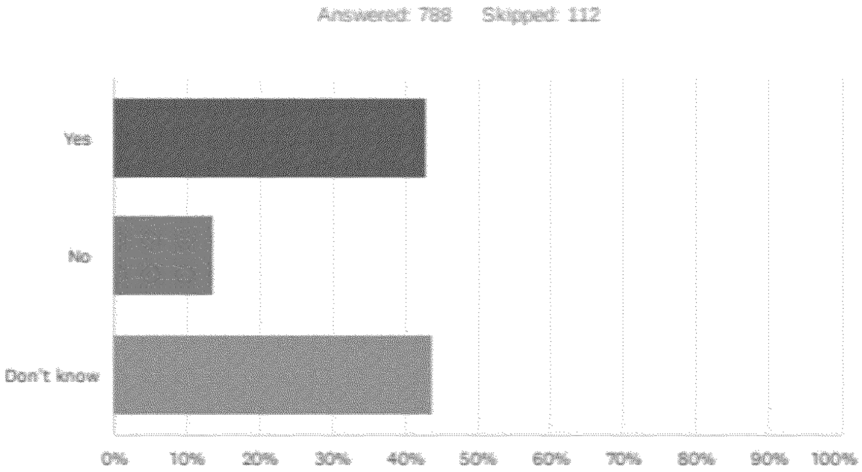


Impact of interferon treatment

During the inquiry we heard from many witnesses about the impact of various interferon treatments available at the time. Some people had to go through more than one round of treatment which often had a devastating impact on the ability to have a normal family life and maintain employment. Many lost out on promotions and had to give up employment which had a severe detrimental effect on career progression. We also know that the psychological impact in some cases caused families to break up.

The pain and suffering from interferon treatment and its associated side effects as a direct cause of being infected by hepatitis C has not been reflected within these categories in the injury or autonomy award.

Q16 - Do you think people who are treated with interferon should form a seperate category?



Quote from an email received 30 May:

"Where a victim was treated with interferon, which is regarded widely among those who have used it as causing ongoing problems related to central fatigue and brain fog, how is that compensated for, when HCV is perhaps wrongly regarded by clinicians as having no fatigue symptoms following 'cure'?"

Quotes from survey:

"I cannot emphasise enough the impact on my husband going through interferon treatment which didn't work and had catastrophic consequences to his mental health."

" I've been crippled with nerve pain due to interferon attacking [my] nervous system."

The impact of these treatments caused long term mental health problems for many people as identified in the list of side effects from the Infected Blood Inquiry's hepatitis expert group:

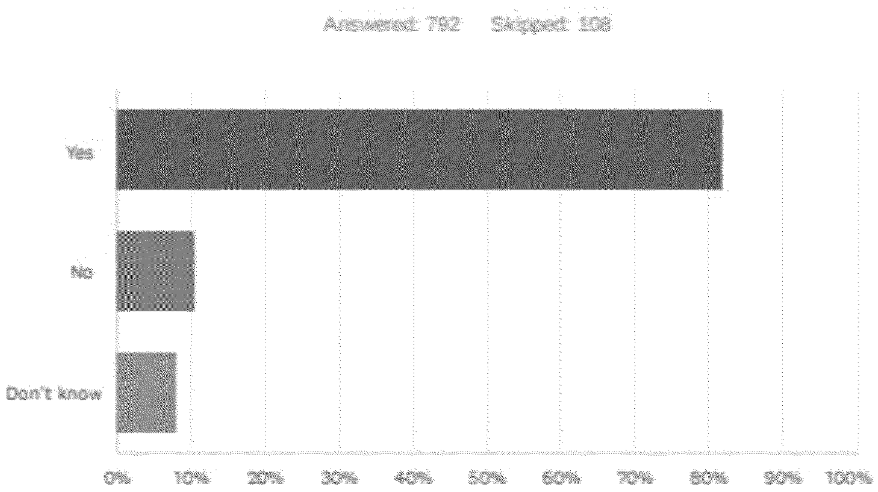
'Psychiatric disorders Depression*, anxiety, insomnia* Aggression, mood alteration, emotional disorders, nervousness, libido decreased Suicidal ideation, hallucinations Suicide, psychotic disorder Mania, bipolar disorders, homicidal ideation.'

(For a full list of conditions see EXPG0000001 - Expert Report to the Infected Blood Inquiry Hepatitis - 01 Jan 2020 | Infected Blood Inquiry p 42-44.)

Impact of being infected and having a bleeding disorder

The experience of living with a bleeding disorder and the additional burden of social stigmas has not been taken into consideration.

Q17 - Do you think higher compensation should be paid to people with bleeding disorders infected via contaminated blood products as compared to people infected by blood transfusions? This would be to compensate for complications from their pre-existing health condition, psychological impact and issues such as stigma, lack of consent and the ignoring of treatment guidelines?



Many people would not even tell others about their diagnosis of haemophilia or other bleeding disorders because of the perceived association with HIV/AIDS. It did not matter which infection they had, people were treated with suspicion and, in some cases, open hostility leading to social isolation. We do not think this has been captured adequately within the social impact award.

We still have members today who ask for post from the Haemophilia Society to be in a blank envelope for fear that their neighbours will know have haemophilia and assume they are infected. Many still feel they cannot be open with friends and extended family about having a bleeding disorder due to the stigmas they have endured.

Quote from survey:

"Persons with bleeding disorders and their families were affected by the same level of stigma/discrimination/harassment regarding HIV/AIDS irrespective if they were infected with it or not - especially during the 80s. Even today some people are still reluctant/cautious about telling others about their bleeding disorder."

People living with bleeding disorders have lived with the fear and impact of hepatitis C for many years.

Quote from an email received 20 June:

**"I have haemophilia and was infected with hepatitis C from the first time I had treatment at 1 years old. I found out I had been infected with hepatitis C when I was 9 years old.
I grew up being told I would die at a young age, in and out of hospital all my childhood missing out on education, giving up on the future because I was told I didn't have one.
Under the proposed scheme I would receive the same amount of compensation as somebody who has only just recently discovered they are infected with hepatitis C."**

Another issue which is unique to the bleeding disorders community was the trial of products without consent, testing without consent and withholding test results.

Quote from an email received 30 May:

"PUPs [Previously Untreated Patients] and experimentation on people with haemophilia. This aspect is truly horrific and needs to be included. In my own case I had a single treatment of Factor 8 that was not medically justifiable this is very different from someone that received several pints of blood without which they would have died."

Finally, those living with bleeding disorders already have musculoskeletal challenges such as maintaining bone density and damaged joints due to bleeds; many of the treatments exacerbated these challenges.

Acute and non-proved chronic hepatitis C

For many who have proven treatment with contaminated blood products and history of hepatitis C infection, there are issues over proving their length of infection. Some have missing medical records and, despite having been treated over many years with products infected with hepatitis C, have not been accepted on to the current support schemes. This is due, in part, to their need for specific evidence such as PCR tests, which were not available in the 1970s and 80s, when these infections happened.

We call on the scheme to examine the evidence required to be accepted into the chronic category.

Quote from email received 4 June:

"There are a number of individuals out there that have not received a single penny of compensation, despite chronic infection, or even acute infection, because their medical records are missing/lost/destroyed or they simply do not meet the arbitrary threshold of 6 months' worth of infection."

Quote from survey:

"What about the impact of those of us infected as children? Those who self-cleared do not have evidence as to whether they self-cleared by 6 months or longer as weren't tested until 10 years later."

Secondly there are people who although are classified as acute have lived with the fear of becoming ill and dying, some watching friends die of these infections. In some cases, this has taken a massive psychological toll on their lives, in addition to the stigma of living with a bleeding disorder.

vCJD

We want to point to the impact of vCJD which again is something that particularly affected the bleeding disorders community. We ask that you take into consideration the psychological affect this had on an already exhausted community.

Quote from an email received 25 June:

"VCJD…I do remember that when I got the letter saying you had batches that were potentially contaminated I remember it was a massive blow. The tv coverage was terrifying, they were talking about 20 year incubation period and no cure, and it kicked out of me a lot of positivity about ever living a normal life into old age."

Progression of disease

Unfortunately, our community is acutely aware that over time the status of health may change, and people may move into a new categorisation which may include additional care needs. This is a concern that has been voiced by our members. How would the scheme work if someone's medical conditions worsen over time?

Quote from survey:

"The banding doesn't account for future deterioration of a person's health."

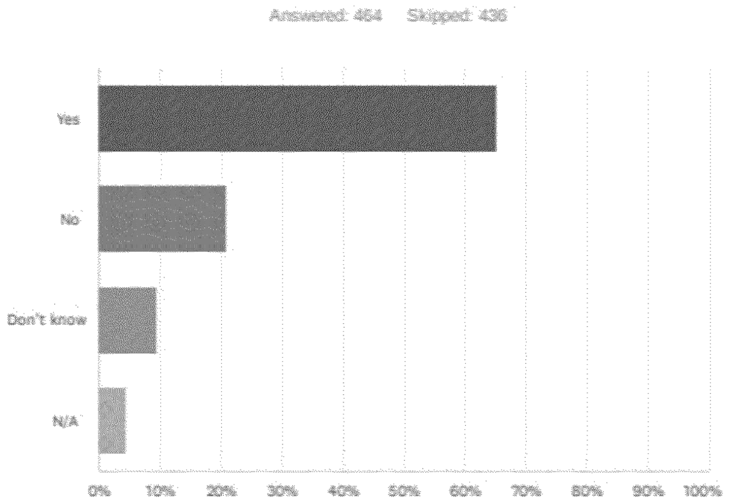
Quote from an email received 30 May:

"How can account be made of future developments of disease in victims when the understanding of that impact is still developing year by year, and so much is likely still to be unknown? How is that factored into the calculation?"

Issues with compensation through estates

For many families, receiving the bulk of the compensation for deceased loved ones through estates may work. However, there are legal, technical and moral issues that need to be addressed. We believe this complex area needs to be re-examined to find ways to reduce the impact of these complications, even if they cannot be completely eradicated.

Q20 - Currently, we believe the majority of compensation for the deceased is to be awarded trhough estates. Therefore, any awards would follow any instructions left in the wills or to be let to the next of kin. Considering your family situation, do you think this would be a fair way of distributing compensation?



We have received many phone calls from people who are distressed by the anxiety around compensation being paid to estates of those who have died.

Estates being entailed away from the affected families

We have been made aware of cases where a will was left which will result in compensation being paid to people who have or had no connection to the original infected person.

Quote from email received 23 June:

"My father tragically died having suffered all his life firstly from having severe haemophilia A and then was cruelly infected with HIV whilst he attended Treloar College as a vulnerable young boy. When my father passed away, he left his estate to his wife. However, his wife unfortunately died a few years ago. This now means that legally if any monies were to be paid into my father's estate from the IBCA it would automatically pass over to his deceased wife's estate whose beneficiaries included, her mother and her then fiancé."
"...as his only dependant I need to fight for what is right especially when my father still has living blood relatives. I find it ludicrous that people who are not connected in any way to my father could end up benefitting from this horrific tragedy."

Morally, it is wrong that someone completely unconnected to someone infected may receive a large lump sum of compensation. There may be other cases where there is no one left even to contest this.

Distribution of the compensation awards

There are also cases where the fairness of distribution is in question. For example, where a marriage has been short lived. The widow will inherit, leaving out the parents and siblings who lived and cared for the infected person. They would receive a tiny portion of compensation by comparison.

This is not an isolated case. Many family relationships broke down under the pressure of physical and psychological trauma. There are children who are estranged from their parents. There are second marriages where the couple may have only been married for a short time and the widow did not take on most of the care. In those cases the family that provided care, such as parents and children, would not benefit.

The pressures of people coping with the impact of infection, and in some cases, treatment led to a high level of breakdown in relationships.

Quote from email received 31 May:

"It has come to my attention recently some information that has worried me regarding my late father's estate. He was co-infected in the late 80s with HIV and hepatitis and died in 1993. At the time of being infected my dad was married to my mum. My mum was shown how to administer the home treatment which ultimately was responsible for my dad's death. This is something my mum carries the guilt of to this day. Unfortunately due to strains contributed by this, my parents separated and divorced.

At the time of my dad's death he was remarried. My understanding from my grandparents is that they had separated albeit not officially. His wife had 2 children from a previous marriage. I was my father's only child, he was married to my mum at the time of being infected and receiving his diagnosis. I was 9 years old when my dad died.

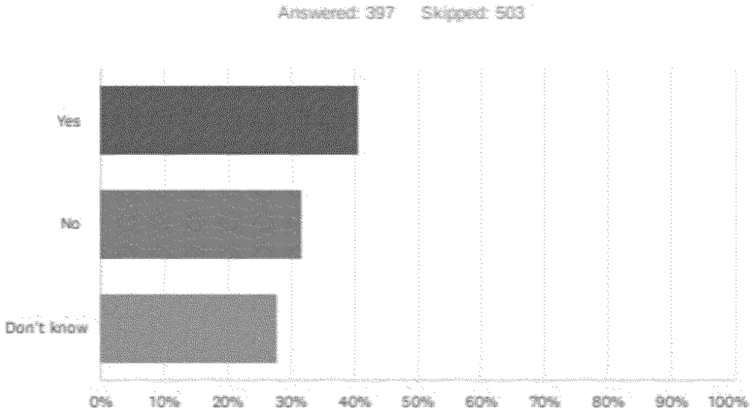
My dad died without making a will, my understanding is that he was struggling with what was happening and struggled to accept he was dying. This meant his then wife became his legal next of kin and applied for probate. To my knowledge I don't believe his then wife has remarried, but I am aware she moved abroad with a new partner after my dad died, and has since moved back to the UK and has been in another relationship.

As a result of my dad dying without a will, I have never received anything from his estate and his wife never made any contact with me, back then or since."

As one person said on a phone call, they calculated that as siblings now they might get less than 2% of what the compensation due to the estate was worth which is entailed away from the living blood relatives. They said the principle is like a "smack in the face for a family who lived through hell watching their brother die".

Even when cordial relationships exist, parents and siblings feel it is wrong that they need to 'ask' for their fair share of compensation from the executor. For example: A sister and parent need to negotiate with their daughter/ sister-in-law to distribute fairly any compensation paid to them. They do not want to be beholden to a relative for money that, as they see it, is due to them, as well as the sister-in-law.

Q21 - Should directly affected family members be eligible for a higher individual compensation payment if this means a reduction in the amount to be awarded via the estate?

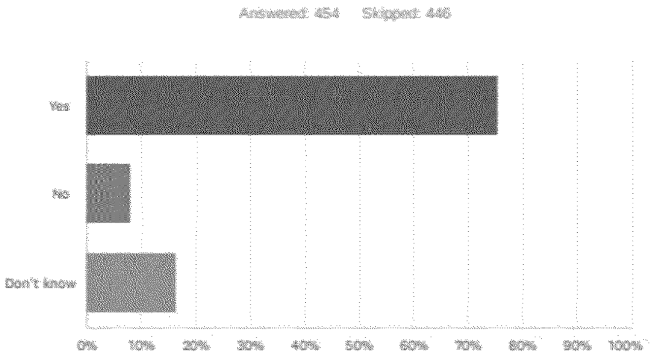


Quote from survey:

"I am also concerned that passing a potentially large sum of money to my mother in circumstances where the affected children do not receive a similar level of award is going to inevitably cause family tension."

We believe this has the potential to cause more irreparable damage to families that have already been through so much trauma. There must be a way to make this fairer system to reduce the potential further harm this may have.

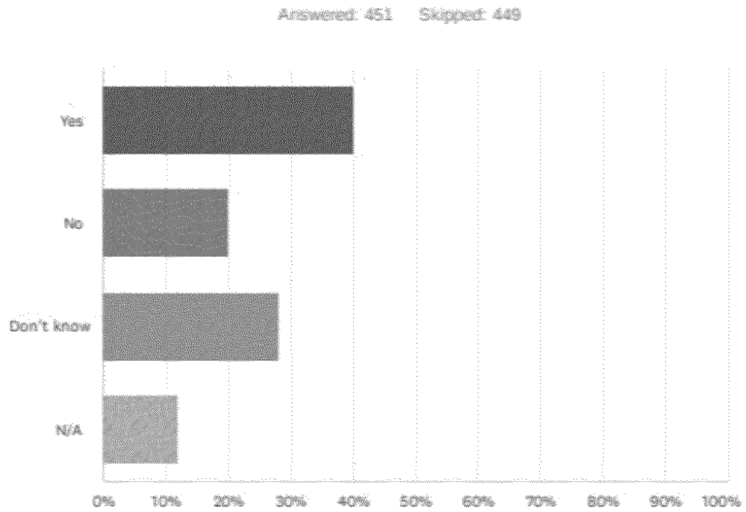
Q22 - Do you think there should be a free independent mediation service for disputes over wills and inheritance?



The care award

As proposed, it is only at the request of the infected person's estate representative that the care award be paid to an affected person. In many cases this estate representative may have no knowledge of the level of care provided or be in contact with the family.

Q23 - Under the current proposals a care award for deceased is paid directly to the affected person but only on the request of the estate administrator. Considering your family situation would this solution work for you?



There are cases where the beneficiary blames the carer, as in some cases these were the same people who gave the factor treatment.

There should be a system where a carer can make a claim without reference to the administrator of the infected person's estate if still living due to the breakdown of families and relationships.

We want IBCA to consider ways to reduce the impact of these scenarios which avoids the trauma of having to contest wills. We also understand that under the 1975 Inheritance Act, siblings and parents are not able to contest wills. This may need to be addressed in secondary legislation.

Alternative solutions

We propose other routes of distribution of the compensation due to those deceased.
IBCA could increase the money paid directly to children, parents and siblings either as a higher set amount or as a percentage of the overall compensation due.

This may not solve all the issues, but a fairer spilt may, from the discussions we have had with some families, be acceptable.

A second step would be to have a dedicated mediation service. This would allow disputes on wills to be considered without the financial and psychological burden of going to court. This would have to be funded by IBCA.

These two steps would reduce the number of wills being contested, reduce the burden on the courts and bring better resolution to more families.

Technical issues

We have been approached by people asking technical questions about estates, intestate wills and probate and how to become administrators. We do not have any of this expertise. Lack of information means that our members are turning to so-called experts in medical litigation and are at grave risk of being exploited. We already know of one example where someone has paid £700 to set up a trust, which is not necessary. IBCA must offer independent legal experts to help with these technical questions.

Quote from survey:

"I think the estate award looks hard to negotiate in this instance as I suspect no will was written, so help with this would be appreciated."

We are grateful for the pro bono advice of lawyers who work within these contentious estates and probate areas who have helped us navigate some of the issues arising, but this is not a sustainable position.

Some common areas of concern are:

- Many people have no idea whether a will was written and since there is no central register of wills this may cause issues with people applying for letters of administration.
- There is the probate register but many, particularly who died young without a significant estate, would not be included.
- This register will not provide any information on post probate challenges to wills, deeds of variation, court orders etc. A paper audit trail relating to estates in the 80s and 90s would be almost impossible to follow.
- The current route for challenging wills is lengthy and could take at least two years. There is concern that the estates could end up paying for all the legal fees, significantly eroding any compensation payment.

We suggest an advisory service be set up as well as dedicated guidance for this community.

Psychological Impact

Although many people can navigate this system, many are very anxious about having to face this level of financial decision-making. Those who struggle with online access can feel very overwhelmed by the whole process. This is causing great anxiety. It is crucial that people experience empathy and patience to help them through this technical and confusing process. IBCA will be aware that bespoke psychological support for the infected blood community in England is still not in place, which is making this situation even worse.

Quote from email of someone anxious over wills on 30 May:

"What happens in the case of a deceased person's will having previously had probate granted to the Executor, who also has subsequently died? In my case, my dad died leaving my mum as executor and she had probate for dad's estate. She has also died. Within the same will, it states that the three sons would then become the Executors and joint beneficiaries in the event that Dad survived Mum.

'I am really confused and stressed at the thought of how payments will be administered. The prospect of me having to communicate with the two other brothers, of which I am estranged from and also having to go via solicitors to sort the estate is causing a significant amount of anxiety.

'It would be preferable if beneficiaries could apply directly to the IBCA as individuals for their share of the compensation due to the estate of the infected person. "

Awards for family members

Separate to the issues regarding the estates payments being entailed away from family members, we think the payment amounts to affected people and family members in their own right should be reconsidered.

We have spoken to many family members who are still living and reliving the horrors they went through as a family.

Quote from email received 8 June:

"I understand there are a lot of families out there with their own story to tell, I understand that the money pot is not bottomless, but I also know our suffering as a family, was and still is very real. "

As we witnessed throughout the inquiry hearings, there is an immense variety of experiences and personal circumstances which are very difficult to categorise. The payments suggested in the various sections for affected people do not always reflect the emotional distress, social implications or interference on family life caused by their family members' treatment and infection with contaminated blood products.

This is particularly highlighted when, for example, the estate payments are entailed away or the family member is estranged, for whatever reason, from the infected person. As we have pointed out earlier the impact of living with infection and all the emotional distress has caused a high level of family breakdown not just between partners but with extended family as well. This breakdown may also prevent a carers award being applied for if taken as is written in the current scheme (see later section on carers).

Therefore, we would suggest that a supplementary route should be available for the affected where the awards within injury, social and autonomy heads of loss could be considered. Under these awards personal issues could be examined, for example;

- Not having children as the partner of someone infected.
- Delaying or cancelling life events such as marriage and job opportunities to support the infected person and family.
- Offering high levels of emotional support to a family member.
- As an adult suffering high levels of social isolation and stigma by being the sibling of someone infected.

There are some within the community that feel that the amounts suggested do not reflect the support they have received.

Quote from email received 21 June:

"The £58,000 for the partner of a haemophiliac suffering from chronic hepatitis C is far, far too low.
My dear wife supported me day by day through 31 years of hepatitis C infection, and through two lots of Interferon treatment.
I think she deserves more than £5 a day for that! I think my sons deserve more than the £3 a day equivalent for their loss of my time and energy during that period. "

Siblings

We want to point out a special case with respect to siblings who were above 18 or did not live in the house with the infected person from 16 at the date of infection of their sibling. Currently they would not be recognised within the award scheme outside of a carers award.

Many siblings have supported their infected family member through very distressing periods of life. Some lived in the family home as adults to help take care of the infected person and were subject to the stigma and social isolation that came with being part of the family. Since the nature of the infection meant that many infected people did not go on the form relationships and have children the siblings have become the support network for the infected person.

We have witnessed at the inquiry the continued support given by siblings, being the constant presence in people's lives who have a true understanding of their experiences.

Quote from email received 20 June:

"From 2003 to 2004 when I had severe depression for over 12 months, and suicidal for at least 6 of those months following my 2nd Hep C treatment, my sister & her partner provided both practical and emotional support, e.g. allowing me to stay at their house, phone calls, etc etc. .... The emotional strain on my sister was immense."

We think again there should be a recognition of the impact on siblings even as adults and as above there be a supplementary route for special cases and circumstances to be taken into consideration.

Children and Siblings

We want to comment on the criteria for children and siblings to have lived with an infected person as laid out in pages five and six of the explainer document produced by the Cabinet Office to provide more detail about the Infected Blood Compensation Scheme.

The document says:

> **Children:**
> **Who while under the age of 18, were cared for and lived with (for a period of at least 1 year) a parent who was, or later became, infected. The age of a child at the time of a parent's infection does not impact eligibility but compensation rates will be higher for children who, while under the age of 18, lived with and were cared for by an infected parent (for at least 1 year), than for people whose parents were infected when they were in adulthood.**

> **Siblings:**
> **Who while under the age of 18, lived in the same household as an infected person for a period of at least 2 years after the onset of the infection.**

Consideration should be taken that parents may have split and there be shared custody of the children, or the children may have attended a boarding school for example. In both of these examples we suggest that this be considered as living with.

It should also be considered that some people on discovery of the infection status of their partner removed their children from the family home or asked the infected person to move. This was, in particular, with respect to HIV and the fear and stigma that surrounded the virus.

In some cases the fear of spreading the infection to children and, in later years the impact of interferon treatment, and the associated psychological impact on the infected also drove families apart.

The infection and subsequent impacts were often a contributor to the family breakdown due to the emotional and financial stress this had on families. Therefore, to penalise a child (now adult) for the actions of their parents who may have been acting in a way they thought to protect them would be wrong. In fact, the infection itself may have robbed them of a closer relationship with the infected parent.

Carers

The role of the carer as reflected by the inclusion within the scheme has been important in so many of the infected people's lives and this care has come from a variety of sources.

One issue we want to examine is the requirement for the care award to be paid to the affected person only on the request of an infected person or their estate representative.

As we have pointed out in previous sections the breakdown in families and estates being entailed away from the family members. This could mean that those who have given care may have no way of being able to receive a care award.

We suggest that there should be a way that individuals who gave care could claim directly irrespective of the estate representative or infected person.

Quote from survey:

"It should NOT be at the request of an estate administrator. In principle it should go direct to the Carers; this may be complicated. There are many broken families and sometimes the 'brokenness' was caused by the infection."

Other considerations

We have identified some additional points which although we may not be able to suggest any solutions to, we feel we should point out as areas that need much more details and clarification. We appreciate there may be documentation that can offer further information on these points however we feel, based on the current information available, these issues are valid to highlight.

Ther are several key milestones used by the schemes to determine the awards that would be granted, and we want to look at these in turn.

Quotes from survey:

"I am concerned about how to calculate my infection date (as a Haemophiliac). I don't know how to calculate the date I was first infected as I wasn't diagnosed on the date of infection. This is important when applying for the 'Siblings' compensation."

Date of Infection

This key date is important for infected and affected people who may want to submit a claim. It is hard to determine when someone was infected, as symptoms may have been dormant for years and testing was years away. Where it is not possible to point to a specific dose or batch, will IBCA take the date that someone was first treated with a potentially infected blood product?

Hepatitis

Quotes from the Expert Report to the Infected Blood Inquiry - hepatitis

For hepatitis B:

"Hepatitis B virus first came into view in 1965."

For hepatitis C:

"In the mid-1970s it was clear that there were cases of hepatitis occurring post-transfusion that were attributable to neither hepatitis A nor hepatitis B, resulting in the term 'non-A non-B hepatitis' (NANBH). "

We know that during the late 60s and 70s fresh frozen plasma, cryoprecipitate, then later factor products were used to treated people with bleeding disorders. In some cases, we do have comprehensive medical notes including products and batch numbers however determining the date of infection would still be difficult.

Quote from survey:

"It's hard to know dates of infection with lost notes to make an accurate judgement."

Would date of infection be first treatment? Would this be different for different treatment categories? What would be the suggested mechanism to determine date of infection?

HIV

Quote from the Expert Report to the Infected Blood Inquiry – HIV:

"Clinical cases of HIV infection and AIDS were first recognised in 1981
1981 The first recorded case of AIDS in the UK."

We know from evidence from the inquiry, including the expert report, that there are acute and chronic phases after HIV infection which could last months or years without symptoms.
We also must consider that products were imported from the US which was ahead of the UK with prevalence of HIV and therefore in blood products.

How would you determine how a date of infection of HIV is to be established, especially in the context that people with bleeding disorders would be receiving regular and sometime prophylactic treatment?

Date of Diagnosis

In some cases, this can simply be determined by the testing that was available at the time for hepatitis and HIV. Which tests are to be used?

However, there were, in some cases, delays in getting tested and diagnosed and we would like to understand how the scheme would prevent people being penalised for something that was in most scenarios out of their control?

Due to nature of hepatitis C, people may have been infected and died prior to routine testing being available in 1991. For example, someone had died from liver disease/ cancer prior to testing being available, how would this be looked at by the scheme?

Effective management

There are also some questions around the cut-off dates for effective management. This would be a factor in the financial loss award calculation.
An example would be the introduction of Direct-Acting Antiviral (DAA) treatments for hepatitis C. The date listed is 2016, however the NHS rationed the use of these medications and some people had to wait much longer to gain access to these medications. It should not be assumed that access was available to all immediately. There should be checks to ensure the dates align with the reality for individuals.

Progression of Disease

It would again be useful to understand the key markers to be used in assessing the development of disease.

Required evidence

Medical records

There are members of the bleeding disorders community whose loved ones died before the beginning of the trusts and schemes to which they may have been eligible to join had they lived longer. In many cases there is a need for the families to recover medical records and some are coming across barriers such as trusts requiring NHS numbers for the deceased. The scheme could help by writing standard template letters, so the trusts are required to deliver medical records and support for people to interpret the information they are provided with.

Care awards

The scheme needs to provide details about the type of evidence required to make a care award. After so many years it may prove difficult to prove the level of care given by individuals to meet the criteria. There are also cases where care has been shared through the family and guidance on how this would work would be useful.

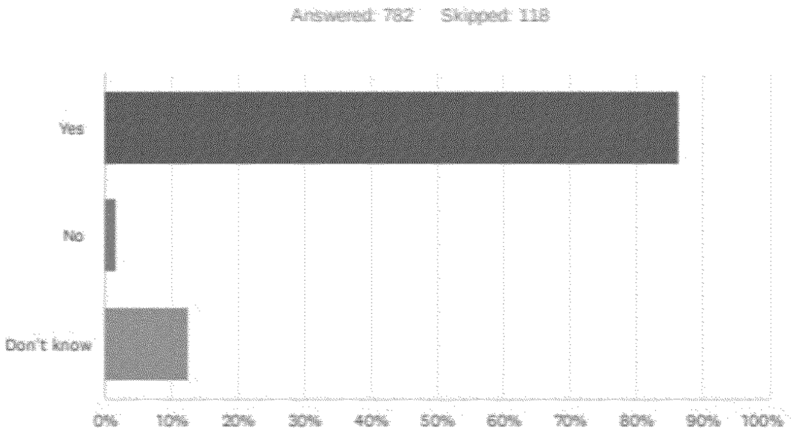
Quote from survey:

"....Myself and my two sisters took care of our father round the clock between us, I would have to give him his treatment, we took turn staying with him, and especially towards the end of life. Sometimes care is a collective responsibility, so how does this fit into the new scheme?"

Equity of payments across the UK

Our members have voiced very strongly that there should be parity of compensation and payments across the UK. There has been variation in payments depending on the place of infection. This cannot be allowed to happen again.

Q29 - Should the payments and schemes be equal across all devolved nations?



Appendix 1

One member's analysis of the value of the current support scheme payments over their remaining life time. This shows that for them they would receive very little compensation on top of the support scheme payments they were currently due to receive.

Current 1 April Financial Year	2024
Age This Financial Year	58
Current IBSS Annual Amount (excluding winter fuel payment)	22,905
25 Year Median Sep CPI (Gov't payments 1 April annual change based on previous Sep CPI)	2.0%

Total Payments		
ONS Predicted Life Expectancy		£
Male	79	625,283
Female	82	733,654

Financial Year	**Age**	**Annual £**	**Cumulative £**
2024	58	22,905	22,905
2025	59	23,363	46,268
2026	60	23,830	70,098
2027	61	24,307	94,405
2028	62	24,793	119,199
2029	63	25,289	144,488
2030	64	25,795	170,282
2031	65	26,311	196,593
2032	66	26,837	223,430
2033	67	27,374	250,803
2034	68	27,921	278,724
2035	69	28,479	307,204
2036	70	29,049	336,253
2037	71	29,630	365,883
2038	72	30,223	396,106
2039	73	30,827	426,933
2040	74	31,444	458,376
2041	75	32,073	490,449
2042	76	32,714	523,163

Financial Year	**Age**	**Annual £**	**Cumulative £**
2043	77	33,368	556,531
2044	78	34,036	590,567
2045	79	34,716	625,283
2046	80	35,411	660,694
2047	81	36,119	696,813
2048	82	36,841	733,654
2049	83	37,578	771,232
2050	84	38,330	809,562
2051	55	39,096	848,658

Appendix 2

We have provided two simple comparisons of expected income from the support schemes compared to a lump sum compensation payment in line with the indicative ranges shows that for Chronic Hep C support payments will exceed compensation after 25 years and for HIV after 35 years for the example payments selected. Full analysis is provided in the supplementary documents **Hep C comparison Income vs lump sum.pdf** and **dual infected comparison.pdf**

The supplementary document **Hep C comparison Financial Advice vs No Advice.pdf** includes two worked examples, with appropriate assumptions on expenditure, comparing how long someone paid compensation for chronic hepatitis C could live off their compensation payments if support schemes were removed. It models an example where the lump sum is invested with financial advice compared to one where the compensation is not invested.

Appendix 3

The full member survey results containing 893 responses is provided as supplementary documents **The Haemophilia Society Infected Blood Compensation Survey.xlsx** and **Data_All_240626.pdf**