

Infected Blood Compensation Framework Scottish Consultation



Infected Blood

Compensation Framework

Scottish Consultation

The Scottish Infected Blood Forum, Haemophilia Scotland and the Scottish Government gratefully acknowledge the participation in this Scottish Consultation exercise of those Scottish, and other, citizens who have been infected and affected by HIV, HCV and other viruses due to receiving contaminated blood or blood products from NHS treatment in Scotland, and the assistance of Martin Bell, Sally Richards and the team at the Scottish Infected Blood Support Scheme.

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The views expressed in this report are not necessarily the views shared by the Scottish Government or Scottish Government officials.

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1. Foreword

Scottish Infected Blood Forum Convener - Joyce Donnelly

It has been said that “an unprecedented disaster requires an unprecedented response”. That has certainly been reflected in the resounding responses received from this Scottish Consultation. They reflect the true nature of this grotesque human tragedy.

For too long Governments in the UK have treated the pressing issue of compensation like a political football, continually being kicked into the long grass. While this ‘game’ was being played thousands have already died and more are dying at increasing rates month after month, year after year.

Ministers and Cabinet Secretaries acknowledge substantial compensation should be paid to individuals infected and affected to match the acknowledged moral obligation the State has to recompense victims.

There is a sense from the four Focus Groups held as part of this consultation, that politicians seem to want to minimise their financial obligation, while at the same time maximise spin and virtue signal how well they have treated victims. Some view this in itself as a form of abuse where the harmer then gets to decide how to make-up for the harm they’ve meted out.

Others expressed the view that UK government politicians may further scupper an acceptable resolution to this disaster by limiting money available to justly recompense people, either by using other disasters as a pretext for that, or by imposing financial compensation obligations for a UK injury/disaster on small devolved administrations and governments within the UK. This, ‘the worst treatment disaster in the history of the NHS’ happened before devolution, on a UK Governed basis. Respondents and Focus Group attendees in particular unequivocally stated that financial compensation should therefore be funded commensurately and centrally from the UK Treasury.

They also expressed concerns at further delays and agreed that the UK Government should make interim lump sum compensation payments as a matter of great urgency. In the context of the harms suffered, an interim figure of at least £100,000 per infected person initially was seen as being reasonable.

To do otherwise would delay justice, a key theme also expressed.

A common question raised at the Focus Groups was how do you compensate for losing a father, wife, son or daughter? In the most practical terms money can help, but it can never make up for the loss of a loved one or one’s health and capacity to care and provide for one’s family.

I would like to express my gratitude, personally and on behalf of all trustees and members of SIBF, to all those who participated in filling out the on-line questionnaire, those who called-in by telephone and those who attended ‘virtually’ the four extremely important Focus Group meetings. I’d like to thank SIBSS and Scottish Government for supporting and assisting this consultation.

Finally, I would like to express my thanks to Tommy Leggate for carrying out this consultation.



Catherine Joyce Donnelly

Convener

Scottish Infected Blood Forum

Haemophilia Scotland Chair - Bill Wright

When we set out to respond to Sir Robert Francis consultation we wanted to try and involve as many of those involved as possible, particularly those in Scotland who have been unable to be heard but have been impacted by the infected blood disaster. So we are most grateful to everyone who responded. We must also thank SIBSS and the Scottish Government for their support in making it happen.

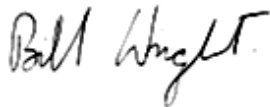
The next steps, based on the evidence from this report will involve a lot of work and persuasion.

Firstly we need to ensure no-one ends up with less than they are already receiving via the existing Scottish Infected Blood Support Scheme - maintaining the monthly payments that now form most people's monthly incomes. They are clearly 'vital' to them.

Second, we need to ensure that compensation extends to those who have not had sufficient recognition. That means providing for those mothers, fathers, daughters, sons and carers who have until now never been able to register with, or claim from, any support scheme, despite the impact on their lives, particularly when losing those closest to them. It also means extending new compensation payments to those already on support schemes. They have only had significant support in recent years, rather than over the decades of loss, pain and grief they faced, when they should have had ongoing support.

Finally, the report indicates considerable hesitancy and anxiety about prolonged assessment and the wish by many to avoid intrusion and delay. This needs to be addressed urgently. However, even the best thought out scheme will not address all circumstances. For those who feel they would be better served by a detailed assessment of their personal case, with legal support, that choice needs to remain as an option. We seek not to stand in their way.

So, with thanks to Tommy Leggate, the report's author, we are submitting this in response to the Infected Blood Compensation Study led by Sir Robert Francis. We also urge Governments, politicians and officials to take heed of the messages it carries and act accordingly.



Bill Wright

Chair

Haemophilia Scotland

2. Executive Summary

Purpose

This Scottish Consultation was devised and designed to inform the UK wide Compensation Framework consultation being undertaken by Sir Robert Francis QC at the request of the UK Government.

While the UK Government has funded the work of Sir Robert Francis, the Scottish Government has funded the work on this consultation. This consultation remains independent of Scottish Government influence.

Background

The “worst treatment disaster in the history of the NHS” has, through the concerted and sustained efforts of infected, affected people, their advocates and supporting charities, over decades, led to a point where the largest ever UK-wide Inquiry (‘the Infected Blood Inquiry’) has been established. The UK Government has initiated a UK wide Compensation Framework Consultation. Scottish Charities, the Scottish Infected Blood Forum and Haemophilia Scotland, initiated this Scottish based consultation in response to this. The primary vehicles of this consultation are an on-line questionnaire, augmented by Focus Group participation.

Community Engagement & Stakeholder Input

The questionnaire was widely circulated to maximise the potential response rate. Infected and affected members of both Scottish Charities SIBF and Haemophilia Scotland were invited to respond. Further the scheme manager at SIBSS (Scottish Infected Blood Support Scheme) agreed to distribute the consultation survey to all beneficiaries registered on the support scheme.

SIBSS has 547 beneficiary members at the time of writing (November/December 2021):

- Around two thirds relate to transfusion cases, and
- Around two thirds are chronically infected with HCV, previously known as ‘stage 1’ infected
- Of these, 51% self-assessed as severely affected, 27.5% as moderately affected and 21.6% as negligibly affected.

The broad make-up of SIBSS beneficiaries are further illustrated in the charts in Appendix D

At 31 March 2021 there were reported to be 3,101 beneficiaries of the EIBSS. The SIBSS membership is disproportionately higher than EIBSS membership given relative population sizes. At the time of writing this report, the constituent make-up of the EIBSS is unknown. The Scottish make-up may, or may not be representative of the overall make-up of the other UK schemes.

Results & Commentary

There were 258 responses during the three weeks of the consultation, from 1st to 21st November. This represents 47% of the SIBSS beneficiary numbers as at November 2021 and exceeded the target response rate. Further, 35 infected and affected people attended the ‘Zoom’ Focus Group sessions which were run in tandem with the consultation survey.

In summary, most people in Scotland who responded...

- Are SIBSS members (96.8%)
- Don't want detailed personal assessments (by a factor of 2.7 times more than those that did)
- Want rapid compensation payments (75.6%), as lump sums (79%), administered in Scotland (67.1%)
- Many wanted an interim compensation payment asap after mid-March (when Sir Robert Francis reports to Cabinet Office)
- As well as SIBSS continuing in existence & making monthly payments (93%)
- Current and past support and ex-gratia payments must not be conflated with, or treated as, part/'payment on account' compensation (94.5%)
- Want Compensation expanded to other family members and carers (77.5%).

Other responses were also received where most:

- Felt split over whether they should/shouldn't take part in a meeting with Sir Robert Francis, expressing age-related mobility issues, lack of trust and lack of transparency issues dealing with UK Government;
- Of those who did, most wanted face-to-face plus 'Zoom' type call-ins.

The strong sentiments expressed from the Focus Groups included the above but also:

- The support schemes (SIBSS et al) should remain and continue to make the planned monthly support payments to infected and affected beneficiaries.
- Lump sum Compensation payments should be from the date of infection(s) and recompense for the past (and likely future) harms of the infection(s) and the past toxic treatments which exacerbated the physical harms.
- These on-going payments are critical to the financial, physical, emotional and psychological well-being of the infected and affected.
- Compensation payments should be funded centrally by the UK Treasury, and
- Compensation payments should not be conflated with past ex-gratia and on-going support scheme payments.
- To do otherwise would only seek to limit the Government's financial obligations due to people and limit Government's moral obligation to substantially compensate victims.
- An interim lump-sum compensation payment should be recommended by Sir Robert Francis in his report to Government, payable as soon as possible after submission of the report.
- As people and families experience the loss of loved ones and the consequences of decades of "grinding poverty" to delay any payments would be to delay justice.

Appendices

A number of useful appendices are included either for information (in the spirit of the commitment to full disclosure), and in particular to achieve the desire to hear people's voices individually and collectively, whilst preserving the fully justified desire for anonymity.

3. Background

“The Worst Treatment Disaster”

In the 1980’s there began to be increasing levels of awareness among medical professionals and some members of the public that a significant number of people were becoming infected by a strain of Hepatitis virus (at the time referred to as “Non-A/Non-B”). It emerged that some people who received whole blood or blood products as part of their NHS treatment were being infected by what became the newly identified Hepatitis C Virus (HCV). This was not only a UK phenomenon, but a worldwide one. It has since been described by the well-known professor, medical doctor and broadcaster, Lord Robert Winston, as “the worst treatment disaster in the history of the NHS.”¹

It is worth noting that the contaminated blood/HCV infection issue coincided with the appearance of the HIV/AIDS virus which received much higher levels of awareness and attention. HCV infection did not receive anything like the level of publicity, political action or medical priority.

HCV infection can occur from a variety of causes, not just by NHS treatments. This can include through the use of controlled drugs administered by self-injection. This particular route to infection, that might involve the sharing of needles, is how many members of the public perceive Hepatitis C infection. However, those infected with HCV through their NHS treatment were far less in the public field of view (and also, perhaps, stigmatised by the limited public perception).

Archer Inquiry

Initially through the government in Westminster, and after devolution through Holyrood, campaigners called for an independent public inquiry to seek answers to why this situation had arisen and to learn lessons for the future. After years of these calls not leading to action, an unexpected and unique situation arose when a non-governmental, but still judge-led inquiry was carried out at the UK level led by Lord Archer of Sandwell². Patients and support groups have continued to see the recommendations of the Archer Inquiry as a reasonable starting point for government to act to support people who are suffering through no fault of their own. Not long after the Archer Inquiry reported, a small financial assistance fund was set up called the Caxton Foundation³.

Penrose Inquiry

The Scottish Government set-up the Penrose Inquiry in 2008. The Penrose Inquiry concluded and reported in March 2015. It did a reasonable job of cataloguing the relevant events as they related to Scotland. However, it was extremely weak on analysis of those events and comparing them to current practice. It failed to establish where lessons can be learned to improve public safety and the lives of those affected. As a result of a weak single recommendation it was roundly criticised as a whitewash by campaigners and the infected and affected community, not just in Scotland, but across the UK.

¹ Lords Hansard text for 22 Oct 2010 22 Oct 2010 (pt 0001)

² <http://www.archercbbp.com/>

³ <http://www.caxtonfoundation.org.uk/>

The Scottish Government issued an official apology and accepted it had a moral responsibility to those affected. Apologies were also made by the Scottish National Blood Transfusion Service (SNBTS) and the UK Government.

Financial Review Group and Clinical Review Group

The Scottish Government established the Scottish Contaminated Blood Financial Review Group (FRG) to review the ex-gratia support payments and subsequently accepted its recommendations. Representatives from Haemophilia Scotland and the Scottish Infected Blood Forum were appointed to the Group.

While elements of the FRG's report are welcomed, the Scottish Infected Blood Forum issued a formal Note of Dissent condemning the continued use of limiting 'stages' to discriminate unfairly on the financial supports being made available for the impacts suffered by people based solely on liver damage, ignoring considerable evidence of extra-hepatic factors and other health impacts.

Due to the unfinished work of the Financial review Group, the Scottish Government established the Clinical Review Group (CRG) in 2017 and published its report in July 2018. Based on compelling evidence, the CRG recommended, amongst other things, that a scheme of self-assessment or self-declaration be established for those chronically infected to assess their own conditions as either negligibly impacted, moderately impacted or severely impacted. These impacts were based on life-changing physical and psychological detriments that considerably impaired the quality of life of infected people, and by immediate association their families (the affected).

The CRG acknowledged the dilemma of the unfairness, impracticality, divisiveness and stress of formal individual assessment, on the one hand, and the failure of a non-differentiating "blanket approach" to recognise differences in viral impact on the other.

The CRG also recommended that, in the context of the life changing impacts of HIV, viral hepatitis and other pathogens on infected individuals, the burden on many of their partners and the widows/widowers/partners of those deceased, a burden which was particularly evident in conversations with SIBSS beneficiaries, must be recognised.

The CRG also clearly stated that Interferon-based therapies used between 1994 and 2016 in Scotland to treat HCV infected people, invariably cause major adverse effects which are debilitating over long periods and these side-effects can be permanent, detrimental and serious.

Scottish Government accepted all the recommendations of the CRG and issued guidance for self-declaration.

Financial Support Schemes

All four devolved nations of the UK set-up their support schemes to provide elements of financial support to the infected and affected people in the UK. The Scottish Scheme was set-up in 2016 and an operational Advisory Group was set-up with victim beneficiary representation. This advisory group's remit is strictly limited to operational matters of the scheme only and cannot make any strategic decisions or make policy-based comments out-with its operational purview.

The four UK schemes have been commended and criticised in equal measure and initially brought about an unequal set of interventions based on the inclinations and will of politicians. This situation

was ameliorated somewhat and parity was eventually introduced at the recommendation of Sir Brian Langstaff, the Chair of the Infected Blood Inquiry. The Scottish Government is generally viewed as being approachable and responsive in its dealings around financial supports.

UK wide Infected Blood Inquiry

In July 2017 the UK Government announced that it would hold a Public Inquiry into contaminated blood and blood products. The Public Inquiry would cover all four nations of the UK. It is the largest Public Inquiry ever held in the UK. The Infected Blood Inquiry began its work in September 2018, it chaired by Sir Brian Langstaff and is not now expected to complete its work until 2023.

Advocacy and support

Those in Scotland impacted by the Contaminated Blood Disaster are served by two registered charities, the Scottish Infected Blood Forum and Haemophilia Scotland. Both charities provide a significant and unfunded voluntary input in an effort to ameliorate the impacts of the disaster on its members and advocate on their behalf when interfacing with Governments.

Haemophilia Scotland

Haemophilia Scotland is a charity for individuals and families with inherited bleeding disorders. It was established in 2012 and provides support, information, and advocacy services in Scotland. It was a Core Participant in the Penrose Inquiry and has trustees and members with decades of campaigning experience on the contaminated blood and blood products issue in Scotland and the UK.

Scottish Infected Blood Forum

The Scottish Infected Blood Forum is the only recognised charity in Scotland that seeks to provide support to all individuals who were infected with Hepatitis C/HIV as the result of NHS treatment from receiving blood transfusions and blood products. It includes people who received blood transfusions and people with haemophilia and other bleeding disorders as well as family members. The charity was established in 2012 and provides support, information and advocacy services in Scotland. Some of its members were Core Participants in the Penrose Inquiry and it has trustees and members with decades of campaigning experience on the contaminated blood and blood products issue in Scotland and the UK.

Since the Penrose Inquiry both charities have sought the best possible Scottish Government response to it by:

- Serving on the Scottish Contaminated Blood Financial Support Review Group (SCBFSG), including conducting the consultation on behalf of the Group.
 - Sitting on the Penrose Inquiry Short Life Working Group, which advised the Scottish Government how best to implement the single recommendation of the Penrose Inquiry.
-

- Sitting on the more recently established Scottish Infected Blood Support Scheme Advisory Group, giving practical advice to National Services Scotland (NSS) about the operation of the scheme, which in Scotland has replaced the Skipton Fund, Caxton Fund and MacFarlane Trust.
- Contributing to the work of the Clinical Review Group conducted by Professor Goldberg which addressed outstanding clinical questions, on the extra-hepatic effects of Hepatitis C and causes of death related to Hepatitis C, arising from the work of the SCBFSG.

A detailed history of campaigning in Scotland is shown in Appendix D.

4. Methodology

The consultation exercise design was conceptually developed through a liaison between the Chair of Haemophilia Scotland and Convener of SIBF. Scottish Government were asked for financial support and SIBSS was approached to gain access to other scheme beneficiaries who are not members of either charity. The criteria that was determined for the consultation follows below.

Scope & scale

The consultation will cover all of Scotland and those individuals who were infected as a result of treatment in Scotland.

The consultation will attempt to include all people infected/affected by contaminated NHS blood or blood products leading to their being virally positive, in particular those whose infection was caused by blood transfusion or through treatment with blood products (as is the case for people with haemophilia or other bleeding disorders).

Definitions

Target Group: The Consultation Exercise will seek to involve all persons in Scotland infected/affected by viral pathogens as a result of receiving contaminated NHS blood transfusions or blood products, including family members and/or carers as well as bereaved relatives.

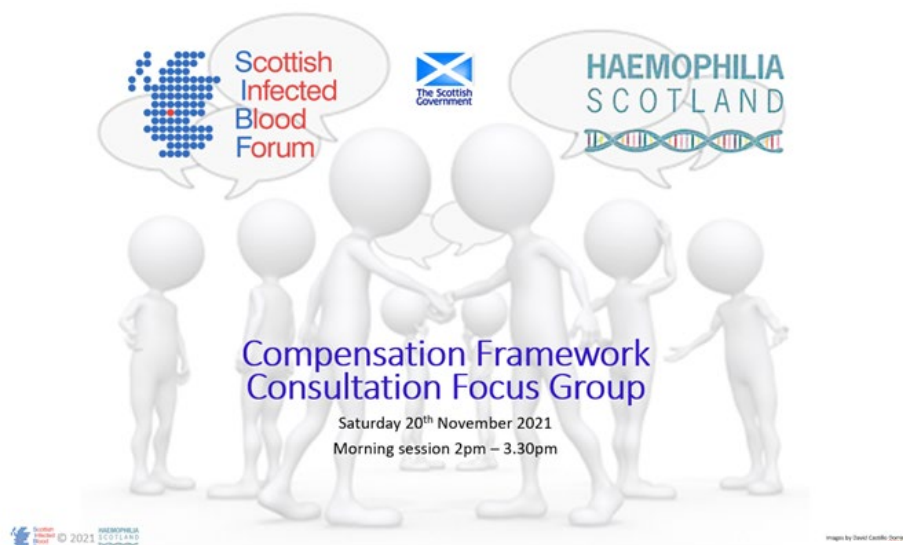
“Infected/Affected”: “Infected” is taken to mean all those with a confirmed diagnosis of HIV and/or hepatitis infection. “Affected” means all those other people whose lives have had to adjust to someone’s confirmed diagnosis of viral infection. In particular “affected” people include family members and/or carers who are not themselves infected, but whose lives are impacted on due to close association with or responsibility for an infected person. This includes bereaved people who suffered a loss as a result of infection. An infected person is automatically also an affected person.

The Questionnaire

The questionnaire was designed to be brief enough to maintain the attention and convenience of respondents, but also focussed enough capture and distil the key elements of Sir Robert Francis’s consultation questions as they pertain to those infected in Scotland.

Providing an on-line survey platform for the infected and affected would aid convenience but it was recognised that a fuller consultation was required to capture sentiments correctly and other information that would be harder to capture via a keyboard only. On-line Focus Group consultation meetings were therefore introduced to allow respondents to further refine their understanding of the key issues of interest to people and provide an open and safe forum to discuss and share ideas candidly and confidentially.

It was also recognised that there may have been a significant number of infected and affected people who were not comfortable or able to respond on-line to the questionnaire. A dedicated phone line was therefore established to allow those people to discuss the answers to the survey questions over the phone with the consultant, who would then input responses onto the questionnaire platform on their behalf.



Focus Groups

The 'Zoom' platform was used to hold four e-meetings to expand and elucidate on the themes expressed in responses. Two were mid-week meetings, a morning and afternoon slot, and two were held on a Saturday, one in the morning and one afternoon to try and accommodate and maximise participants' availability, for those working and those with children etc.

Meetings lasted typically 1 ½ hours and 35 infected and affected individuals participated across the 4 meetings, with the Thursday afternoon meeting being the most attended.

These meetings captured more detailed and thoughtful responses than could reasonably be expected from the online survey alone.

The meetings were facilitated by the consultant and chaired on behalf of both SIBF and Haemophilia Scotland by Bill Wright, Chair of Haemophilia Scotland.

The potential for raising expectations

It was identified as a risk that there was a possibility of raising the expectations of the participants (and the general cohort of people infected/affected) as a result of carrying out the compensation consultation. While a key reason for commissioning the consultation was to identify the needs of those infected in Scotland around compensation, there might have to be limitations to any governmental or other body's responses due to a variety of factors.

Both charity patient representative groups were particularly aware of the strength of feeling among some people, who felt ignored, treated unfairly or in some other way had suffered detriment by statutory or other bodies. While there might be some whose expectations would go beyond the remit of the consultation, nevertheless to go some way to overcome this specific risk from the outset, reference was made to the issue of potentially raising expectations in the Focus Group discussion meetings.

Success factors

The following were identified as indicators of success in the project:

- The report is delivered on time and to a high standard of writing and analysis (the charity representatives stressed the need to see an emphasis on a quality result as opposed to one produced to a short and limited deadline);
 - Over 100 individuals participate in the study and the cohort is representative of the main modes of infection with contaminated blood (blood transfusion, therapeutic blood products for haemophilia and inherited bleeding disorders, secondary infection from someone infected by blood or blood products);
 - Representation covers the majority of (or all 14) regional NHS Boards; and
 - Participants endorse the report findings as representative of their experiences.
-

5. Community Engagement & Stakeholder Input

It was central to the successful delivery of the consultation that it reached out to the correct groups of people. This included individuals infected/affected by HIV and/or viral hepatitis by a particular route, as well as those groups or organisations with an interest in that cohort of people. Thus, the consultant worked closely with the relevant stakeholders to identify people and seek to invite their participation in ways amenable to them.

In practical terms this inclusive and empathetic approach required the involvement of the partners in raising awareness of the Scottish Consultation through their various channels. With the online version of the Questionnaire being the main tool to both generate data and carry out the quantitative analysis, this meant that in practice some peoples' responses were recorded on paper by the consultants then transcribed to the online version. This was in recognition of the prerequisite that in order to have people choose for themselves to participate, then any barriers such as digital access should be minimised as far as possible.

Target Participants

The Consultation exercise sought to involve at least 100 individuals who are infected and/or affected by viruses as a result of contaminated NHS blood or blood products. This included patients, family members, bereaved relatives and carers. These people formed what is referred to as the "community" with whom the consultation sought to engage. It is recognised that this community is not defined geographically (other than mostly being spread throughout Scotland, though some respondents lived outside Scotland and the UK), neither is it defined by socio-economic factors or other demographic criteria, such as ethnicity, gender, sexual orientation, etc.

As a social research activity, ethical standards were followed and principles for community engagement were applied throughout to facilitate informed, person-centred participation. This supported the requirement to take an empathetic approach when asking people about compensation issues closely tied to their personal health experiences of contracting and living with the hepatitis and/or HIV viruses.

It was understood that some people would be harder to reach for a variety of reasons, including isolated geographical location, lack of access to ICT, sense of embarrassment or shame, denial or avoidance, infrequent contact with health services, etc. The consultant worked with representatives of the Scottish Infected Blood Forum and Haemophilia Scotland, Thompsons Solicitors (the recognised legal representatives for the vast majority of Scottish core participants), SIBSS and Scottish Government officials, to seek the involvement of as many people as possible.

It is pleasing to note that the community engagement process was successful and exceeded expectations. 258 people took part in the consultation as either infected or affected persons. This is significant given that the numbers of beneficiaries in SIBSS is 547 (as of 26th November 2021).

This is indicative of the strength of feeling within the community and the effectiveness of the partner organisations in encouraging people to participate.

6. Results & Commentary

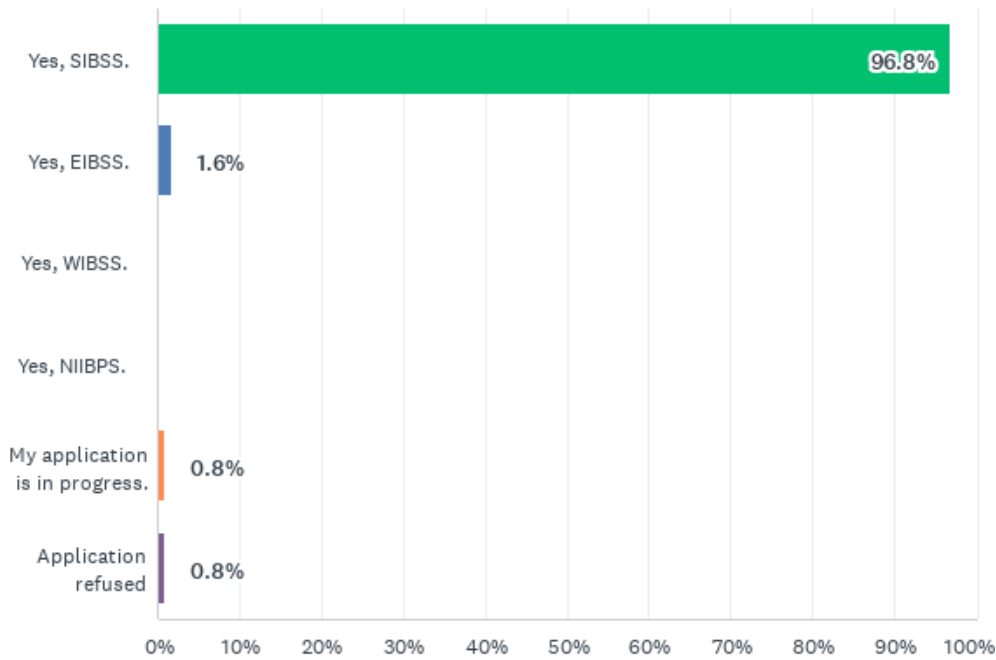
By applying the methodology and following the engagement aims, a questionnaire was designed, tested, refined, and issued. It was made available on the on-line platform for individuals to complete themselves and maintain their anonymity in the process. For the purposes of inclusion, the option of telephoning the consultant on a dedicated phone line was available; for example, if someone was unable to use computer-based technology for whatever reason. These responses were then uploaded to the platform as they were received.

The full questionnaire is included as Appendix A. This main section of the report contains the results obtained as people completed the questionnaire.

The results and commentary follow overleaf.

Q1: Are you registered with any of the UK Infected Blood support schemes?

Answered: 247 Skipped: 11



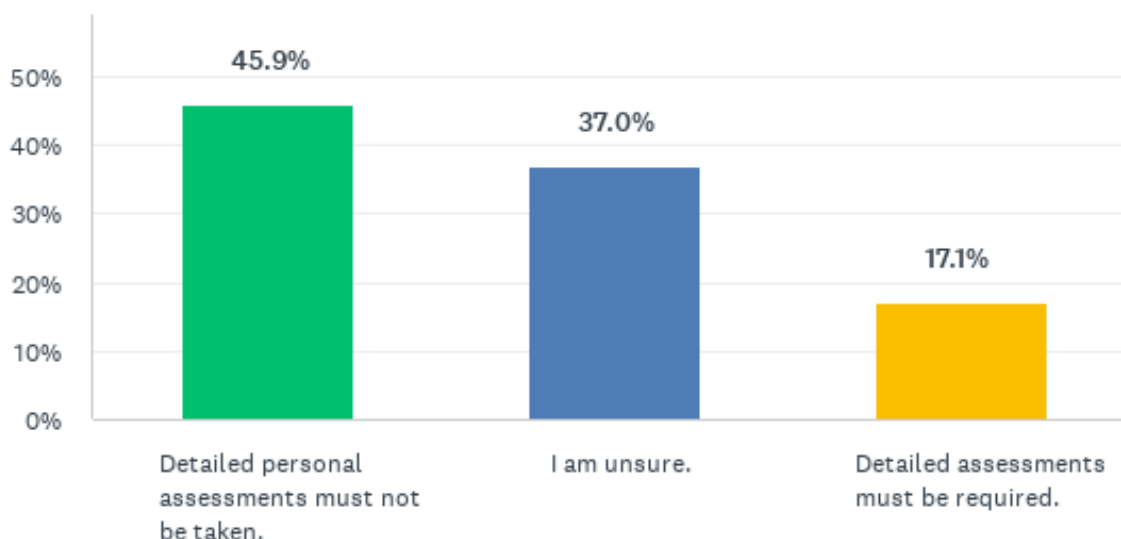
ANSWER CHOICES	RESPONSES	
Yes, SIBSS.	96.8%	239
Yes, EIBSS.	1.6%	4
Yes, WIBSS.	0.0%	0
Yes, NIIBPS.	0.0%	0
My application is in progress.	0.8%	2
Application refused	0.8%	2
TOTAL		247

Most respondents (239) are members/beneficiaries of SIBSS. Notably, 4 respondents are members of EIBSS but resident in Scotland. 2 were having their applications to join SIBSS assessed at the time of responding and 2 were refused applications to SIBSS due to incomplete medical records.

A small number (11, 4.3%) skipped this question.

Q2: To access any compensation payment, please indicate your willingness to undergo a detailed personal assessment based on what has happened to you, even if you have previously undergone an assessment for any other reason.

Answered: 257 Skipped: 1



ANSWER CHOICES	RESPONSES	
Detailed personal assessments must not be taken.	45.9%	118
I am unsure.	37.0%	95
Detailed assessments must be required.	17.1%	44
TOTAL		257

The majority say “No”, they do not want to undergo any detailed personal assessments (2.7 times more than say yes). There is a sizeable amount who were unsure of how to answer - this may be due to uncertainty around what a detailed personal assessment meant to them. Excerpted below are a selection of explanatory comments arising from the questionnaire and the Focus Group discussions:

- *For the Compensation Framework, if you are registered in a scheme (e.g. SIBSS/EIBSS etc.) you should be automatically accepted into the Compensation scheme.*
- *We have been assessed at the hospital(s), assessed by a former scheme(s), assessed in part to move to the new scheme, assessed for discretionary grants, assessed of employment-related benefits, assessed for disability-related benefits (PIP, etc.), self-assessed for SIBSS using unsuitable criteria, assessed in part to be a core participant in the Inquiry. Enough is enough.*

- *Regarding assessments, I'm on my 3rd professor now (other 2 have died) and he says if anyone was to assess me they'd think I was alright and I'd get no sympathy!*
 - *I look okay on the surface, but underneath I'm a wreck, but I'm also a survivor. I don't think I could handle any form of assessment now - I'm terribly anxious.*
 - *This is a central issue. I'm not actually surprised about the "I am sure" amount of 37%. Assessment can mean anything from having to prove that you fit into a particular category to the opposite extreme, a damages equivalent assessment where you would go through a full assessment of a your income and loss in income, and that gets very complicated for someone infected as a child who might or may not be a means of going to university. So it's a really, really difficult issue. It can involve a long time. In some cases, it may be several assessments.*
 - *I think some people were unsure how to answer the question because there may be confusion about what a personal assessment is and means testing. A personal assessment is looking at your health impacts and associated impacts related to the infection or how you feel or how you've been damaged or hurt. And usually that's regardless of how much money you get. It's just totally how have you been affected? Whereas means testing is usually how much money you have got already regardless of how sick you are, i.e. if you've already got enough money, you don't need to be given any more money. And that's what they do to target money to where it's needed most. I think that the 'I am unsure' people weren't sure about the differences if they hadn't had it explained to them. There's nuances behind having tariffs or having to justify your individual harms in some way, then that's why I think some people may be unsure.*
 - *Basically, "means testing" = how much money have you already got and "assessment" = how sick are you.*
 - *And I think in terms of our family, which are a bereaved family, it is so difficult to quantify and that if you were going to have a detailed assessment, in terms of what you've lost and then and also in terms of what my what my husband lost. And, briefly, when my husband was first diagnosed, he had a really good job. And then as the years went on, as the effects of the hepatitis and the treatment took its toll, he was on a minimum wage job and then no job and then, in terms of my kids both of them watched their Dad be sick and then lost them when they were in their teenage years, which meant that their education was completely interrupted and therefore their ability to go into further education and obviously more lucrative employment was affected. And how also can somebody quantify in an assessment, the emotional devastation and the emotional harm. Both of my children suffer from mental illness, completely due to what's happened?*
-

- *Well, I can relate exactly to that, because that was my position as well, with my husband, we were on 'half pay' a number of times before he finally had to give up work altogether, and like you, my children were teenagers and they were growing up with this father who wasn't quite as he had been. And is this what a family relationship is like and as I say in those days, there was no counselling. There was no counselling for my husband at all, which I really, really resent. He was just left to get on with it. There was no counselling for him. There was no counselling for me. There was no counselling for the children and they did suffer. They did suffer. I mean, they did continue their education but you don't know the harm that was done in all this uncertainty of their father's condition, which, well, we don't talk about it kind of thing, you know, trying to be pleasant and put up with it. You can't quantify it. Again, I wasn't sure how to answer the question. I think I may have said I am unsure because this idea of 'means testing'. I mean, other than Skipton, we had never applied to Caxton or McFarlane because I'd heard that some of them were means tested and I didn't want to go down that road, but I'm still unsure I would imagine.*
 - *Well, I've got a daughter as well and she's been affected, even though she's got family herself now. And she asked a few years ago when she actually knew the real things that was going on in the past and asked why we didn't have more children. She also said she wanted another brother or sister. I had a vasectomy after being told the wrong information. My worry is this just going to be someone else who's going to assess you, who has not got an idea of what this Inquiry's all about and the suffering people have had. Are they just going to have a PIP assessment and you go in and the person who's writing it down doesn't know the background and history about it? I just don't trust the government on this at all. I think it's just a claw-back money exercise.*
 - *I totally agree and I think that all of us have suffered a huge amount. And I was sure I didn't want a detailed assessment. And I think that other than to say to prove, yes, I was a wife and for them to prove that they were children and we have it on his death certificate 'that's what he died from', that's obviously the best thing, but we've had to do already. But I think to put suffering people through even more suffering and to somehow have to say to complete strangers, who are office personnel, how that they were affected, I just think it's just not on. I really do. I just think that is just adding insult to injury.*
 - *Yeah, but they're very mixed thoughts, really. And that's one of my problems. Thinking about it, I see compensation about recompense for a loss that has been suffered. And in some cases, you can easily test that. But without doing some form of detailed assessment, I can't see how you can give a proper figure for what the losses that's been suffered and what the monetary value of that is. I wouldn't want a detailed assessment. I mean, PIP and things like that just bring up thoughts of horror stories in people's minds. But there's probably going to have to be something in there which does an assessment.*
 - *If there was to be a health assessment, that means that we're then reliant on the very profession to do the assessment that a lot of us feel very cynical about in terms of the*
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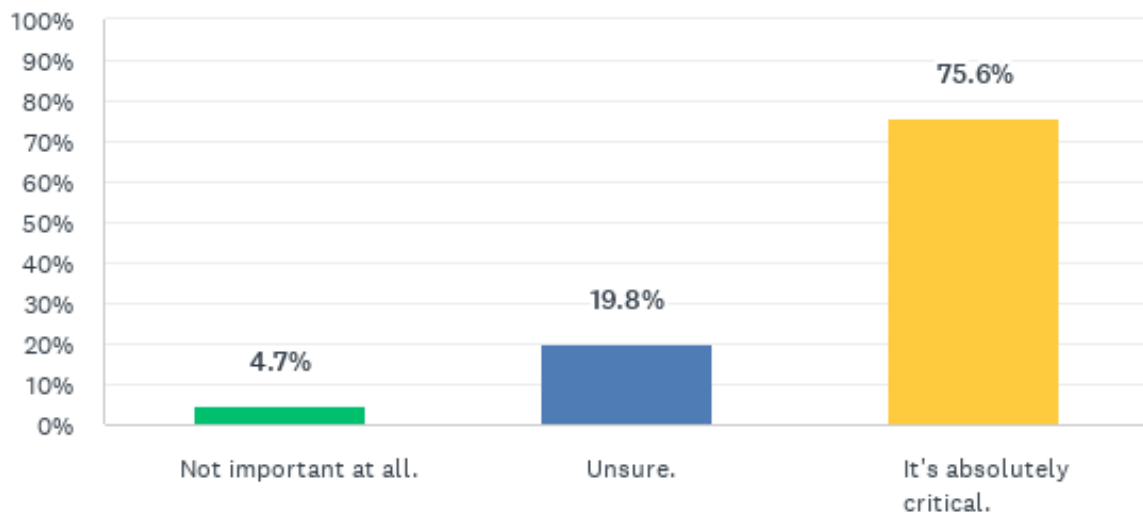
medics. And actually, to be honest, I don't think a lot of the medics particularly want to do those assessments.

- *It's just this is a crucial aspect of the competition framework study. Fundamentally, people are being asked if you want to get everything that you think you're entitled to then you need to stop worrying about the hassle of having to be individually assessed, because that's what it's involving. However, if you don't want that, then a significant chunk of people may not end up getting as much as it would get if they went to the court on their own route. And then it's a case of, well, how much am I prepared to be community focussed about this for the sake of the greater good, everyone gets a decent amount and those who would have got a larger amount have to be willing to accept that they'll go with the flow with the majority. Because in the same way the core based assessments are normally done. Down to the level of detail like what job did you have, how much money were you earning and what could you expected with your promotions and end up earning. But that means that you're putting people in that situation up against those who find out when they were teenagers, they were to die in five years so they never bothered their back sides about getting themselves a decent education because they weren't ever going to be able to use it. And lo and behold, they survived. And so they spent their life on benefits or minimum wage jobs. They will have been double detrimented because it's not properly taken account of what they could have got, so there's a degree of generosity of spirit required if we go down the route of having tariffs.*
 - *I think it should be a flexible or a hybrid system where if people want to go down the tariff route because of their circumstances and could maximise it there in most circumstances, they could do that. If people want to go for a tribunal route, to take a more formalised option to make an assessment of loss of earnings etc., then they could be able to do that also. We don't want a limited one size fits all, where half of the people are going to be disenfranchised. We wanted that flexibility for the infected and affected to go down the route that most suits their circumstances and availability of evidence.*
 - *I believe people should have the right to go to a tribunal or even seek court damages if they want to. That is why I support lifting the time bar, for example. The benefits of an adversarial process (court/tribunal) are that a person may get more money based on them maybe having, say, lots of lost income if they had to give up a high paying job. They also get "to have their day in court". However, a person could get a lot less money if the opposing lawyers do their job too well, and be further exposed to re-traumatisation, regardless of the outcome. Time delays is also a big factor.*
 - *People should be treated FAIRLY, and EQUALLY. Within a tariff system, everyone in a particular category gets the same (fully commensurate amount for that damage), but that does not need to mean all tariffs are valued the same.*
-

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- *Regarding assessments and self-categorisation, could it be rather than somebody having to be faced with a band of questions, that that was the same idea, that you could have a self-categorisation, if you like, of what you think you've lost?*
 - *One of the reasons is that it's such a complicated area in relation to the points discussed here is that it's not simple, but maybe in the least is the issue of choices. But if we're going to offer people choices about this, then they really need the in's and out's explained to them of what would be involved in going through an assessment. And that's where I think the fault has been to date in all of this. So in other words, it needs to be more thinking and more discussion about this particular element of it. Generally, there's a scepticism about assessment. We don't like the idea. But for those who think that, we really need clearer guidance, more thinking about it.*
 - *I'm not sure what 'tariffs' mean. Tariffs in my mind is generally a score, a range whereby for certain things, loss of a hand, loss of a finger, you get so much money. But for the infected and affected in our circumstances it's not so dry cut as that - there are a myriad and multitude of harms and detriments that follow on from HCV and the past toxic treatments for it, the psychological impacts, the barrage of holistic harms that you can't 'see'. People are ashamed, they try and hide their psychological impacts. But they can't hide it from their families and children and they get the brunt of it oftentimes.*
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Q3: How important is it that you receive compensation payments rapidly?

Answered: 258 Skipped: 0



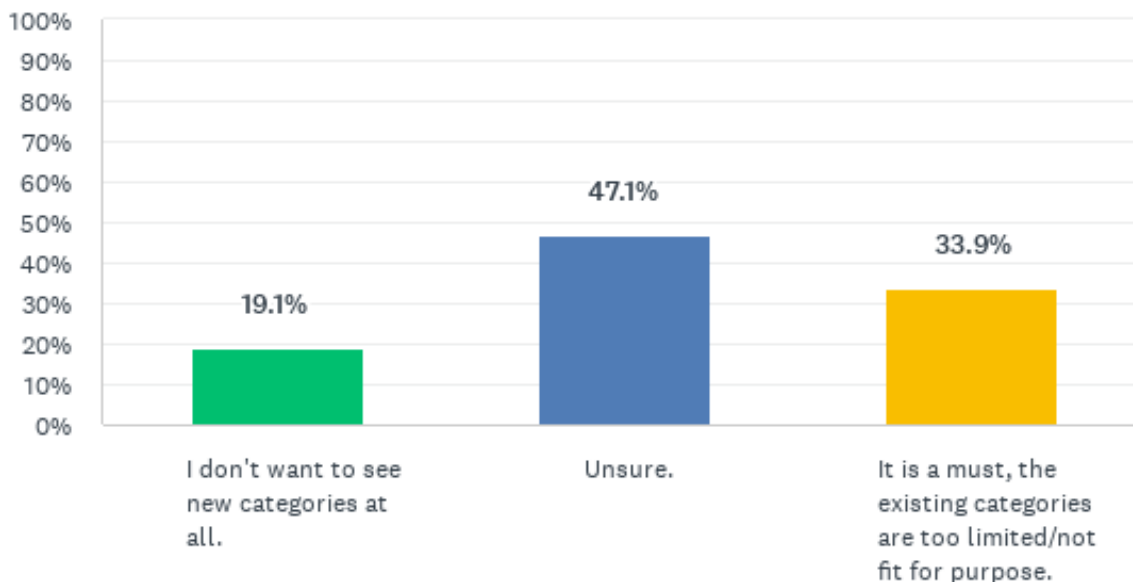
ANSWER CHOICES	RESPONSES	
Not important at all.	4.7%	12
Unsure.	19.8%	51
It's absolutely critical.	75.6%	195
TOTAL		258

Over three quarters of respondents said it was critical compensation payments were paid rapidly to them. Just under a fifth said they were unsure and a small minority (4.7%) said rapid payments were not important to them.

All attendees at the Focus Groups agreed compensation payments should be made rapidly, with a consensus that interim compensation payments be paid as soon as possible after Sir Robert Francis reports to the UK Government. The view was that people are getting sicker and the rate of deaths seemed to be getting faster (9 SIBSS beneficiaries died in a 4 month period to November 2021) and so further delays in paying interim compensation was a further delay in justice being given to victims.

Q4: Indicate your degree of willingness for new categories of payment to be established beyond those in the present support schemes.

Answered: 257 Skipped: 1



ANSWER CHOICES	RESPONSES	
I don't want to see new categories at all.	19.1%	49
Unsure.	47.1%	121
It is a must, the existing categories are too limited/not fit for purpose.	33.9%	87
TOTAL		257

This question related to the support schemes and not compensation. Just under half said they were unsure if new categories of payments should be established for SIBSS. Most of the remainder said yes, new support scheme categories should be established.

Some comments from the Focus Groups are below:

- I'm surprised by that until I think about it. There's those of us who are close to this and it becomes our daily air that we breathe. But there will be many people thinking 'category of payment, what does that mean?' They don't realise that it's not just loss of income, it's all the different things that can be included as a sense of loss or damage. Some of them have got weird names that you've never heard of unless you speak latin. So in relation to the schemes, what this tells me is that people need the categorisations explained to them better*

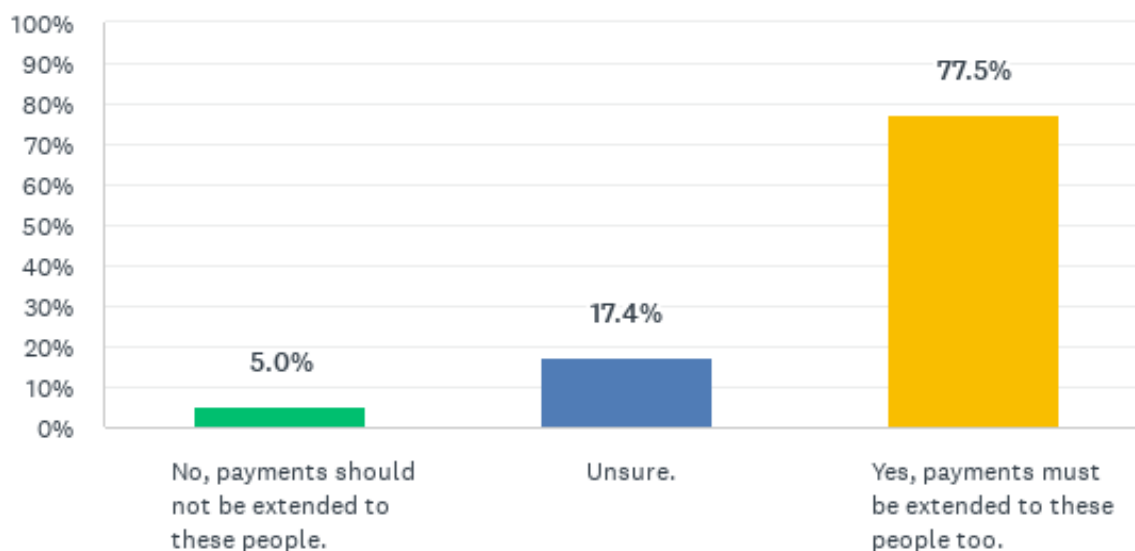
- *Reading a lot of forums there's a lot of people who talk about the fact that it should just go to say, one member for the bereaved family, so it should go to should go to one particular person, say the widow, and then they would be responsible for distributing anything that came along - which would work on my particular family, but I'm also quite well aware of other families that wouldn't work at all. And if you take only the primary beneficiary the way it is and I'm talking about the bereaved beneficiaries, if you take that into account, just being one thing, it doesn't take into account the fact that so many families. partially to do with the whole situation are divided, people have remarried and I think that minimises the individuals who are affected, whether or not, say it was a more likely, I'll say, a father who's died or been infected (not even necessarily died) and moved on to a different partner, does that leave the previous family as not going to be included in any form of compensation because the widow or widower is the primary beneficiary and is therefore got control over who and who shouldn't then get further compensation. Although my family are together, I think that's wrong. I think that people should be in a category by themselves.*
 - *We should treat each member of the family as individuals rather than a single unit.*
 - *The current support schemes actually in a sense only look at the family as a whole because if someone's widowed, then payments continue for the widow. So there is an element of the current arrangements being on the basis of one family. That in itself, I personally think is wrong because, there could be a family who have split up, oftentimes because of the stress and strain of having been infected. And therefore one family is then disenfranchised and left behind whilst a new family unit are in the mix, if you like. And that's why I think individually each, a son or a daughter or a parent, should be included as their individual person because otherwise people Say, for example, my husband and I split up and he'd married somebody else, but his children had lived with the effects of his disease all their lives, then under that case they are not entitled to anything in their own right, and I personally think that's completely wrong.*
 - *I'm naturally very concerned about anything that drives us towards something that like a courtroom based assessment of compensation. However, I think we can use some of the knowledge through case law, etc. in compensation schemes as a starting point guide as to the ballpark figures that might be eligible for types of losses that many people suffered. But in reality, Court based compensation is actually more open than the current financial support schemes, where beyond the individual infected the only other person to get anything is the spouse or widow, after they die. So, as an individual who's a child of someone who died, I would be able to make a claim in Court and get compensation for their loss. You can't go to the schemes and do that (at the moment). So we need the schemes to be opened up as well, or if they're not opened up, then the needs of those who are not in the schemes has to be an 'add-on' for what they don't get from the schemes that others do get.*
 - *The legal framework, if you lost an arm, a hand or a foot, for example in a road accident, you will get £X amount, that's what the lawyers normally pay for. But this is out-with that.*
-

This is a one-off. The Government have never done this before. You've got to think out of the box. £20,000 for a road accident, but for this, where do you start? You've got medical ethics issues, human rights issues, you can name it, but there's been no precedent so far in this country of what we've actually been through and that's why I'm worried. They're not going to look at what it's done to you all throughout your life. So they need to look at the bigger picture as in what the Government have actually done to us rather than in simplistic terms.

- *There would need to be a degree of consultation if Sir Robert Francis was suggesting any sort of such categorisation, there would need to be a further consultation on that sort of thing.*
 - *Someone said, what makes you different from Grenfell? It is different on so many different levels.*
 - *An unprecedented disaster requires an unprecedented response.*
-

Q5: Please indicate your willingness for payments to be extended to new categories of people who should be eligible for compensation, for example families and others affected (sons/daughters, mothers/fathers, carers etc.) even if they have not been able to access any financial support schemes previously.

Answered: 258 Skipped: 0



ANSWER CHOICES	RESPONSES	
No, payments should not be extended to these people.	5.0%	13
Unsure.	17.4%	45
Yes, payments must be extended to these people too.	77.5%	200
TOTAL		258

The vast majority said that compensation should be extended to families and other carers of the infected person. 17.4% were unsure, and some expressed concern that extended categories of compensation may dilute what funds are available for them. Others rebutted that by saying compensation levels should be based on the harms inflicted and not by the size of purse the harmer has.

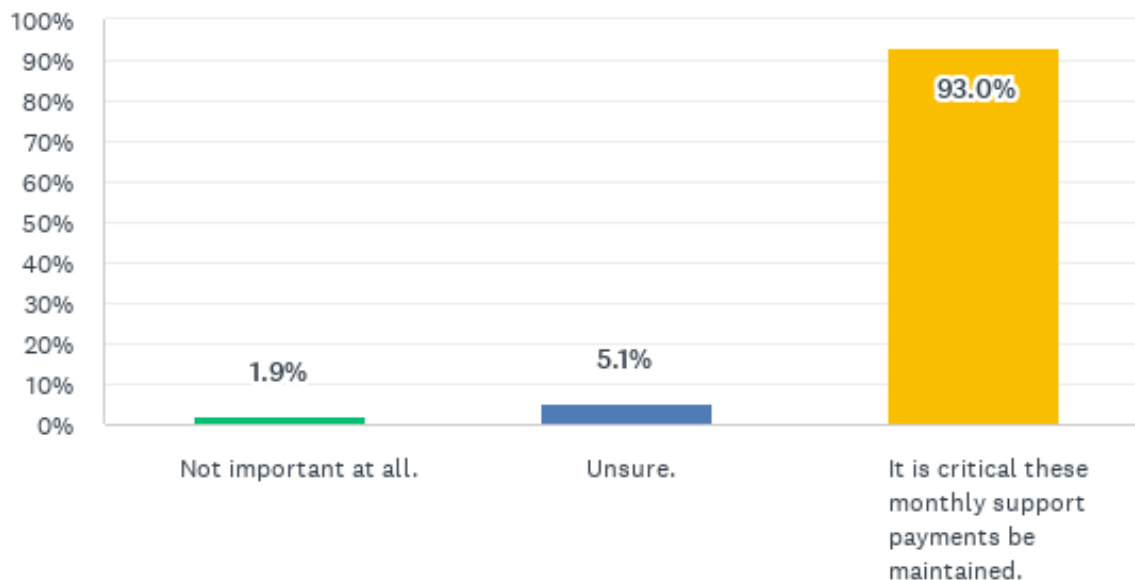
Some comments included:

- *I can only say I feel for the wives and partners that they don't (yet) get compensation with what they had to go through.*
- *It is very difficult for carers to talk about their experiences in front of those infected because they do not seek to inspire guilt on loved ones who have suffered almost unspeakably. From an individual perspective, caring for those rendered sick amounts to the*

definition of modern slavery. We were prisoners of love, and when our loved ones sought to end their suffering, treated like a jailor.

Q6: How important to you is the maintaining of monthly payments under the present support schemes?

Answered: 257 Skipped: 1



ANSWER CHOICES	RESPONSES	
Not important at all.	1.9%	5
Unsure.	5.1%	13
It is critical these monthly support payments be maintained.	93.0%	239
TOTAL		257

This was viewed as a topic of paramount concern for respondents.

The response was unequivocal. The vast majority, 93%, said it was critical that the support scheme payments be maintained. Compensation should not be full and final and *subsume or replace* the support schemes.

On this matter, peoples’ comments included:

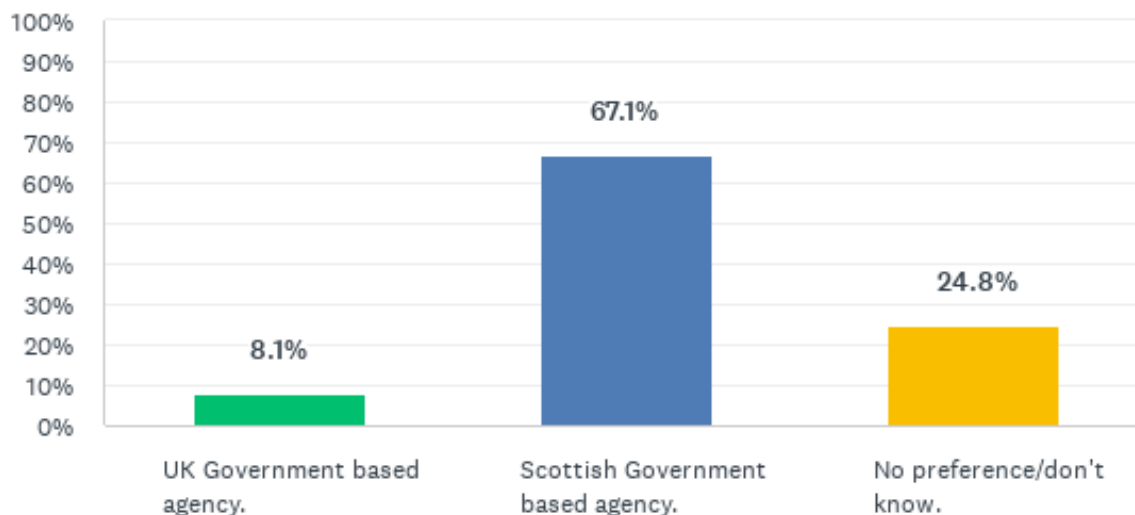
- *For many people the support scheme payments are their main, if not only source of income.*
- *People rely on the regular payment they receive from the support schemes.*
- *To scrap something many people fought long and hard for because it’d be cheaper for the Government is an outrage, a disgrace.*
- *There are many people who’ve actually took out a mortgage on the back of getting letters from Scottish Government to show that the SIBSS payments are effectively for the rest of*

the person's life and then extended for the surviving spouse. Mortgages have been extended on the basis of people being able to get these letters from Scottish Government. And that's the only reason they were granted.

- *People class these support payments as like a pension. They rely on it, they depend on it to sustain the roof over their head and pay to heat, to clothe and feed them.*
 - *The meaning is in the title: it's a 'Support Scheme', it's not compensation payments.*
 - *SIBSS must be maintained, people's lives and families are disrupted, people have been put through pain for years and have to live with an uncertain future.*
 - *It's a disgrace that UK Government might want to treat SIBSS and other scheme payments as any type/form of compensation. The SIBSS payments are support payments and are to be paid to me for the rest of my life and my wife until the rest of her life. To conflate the two is a disgrace and seeks only to minimise the compensation pay-out the UK Government will make.*
-

Q7: Please indicate your preference for compensation payments to be processed through a UK Government based agency (i.e. from London) or Scottish Government based agency (i.e. from Edinburgh).

Answered: 258 Skipped: 0



ANSWER CHOICES	RESPONSES	
UK Government based agency.	8.1%	21
Scottish Government based agency.	67.1%	173
No preference/don't know.	24.8%	64
TOTAL		258

Over 8 times more people want compensation payments administered in Scotland as opposed to London. A sizeable quarter were unsure or had no preference.

One Focus Group attendee summed up the sentiments:

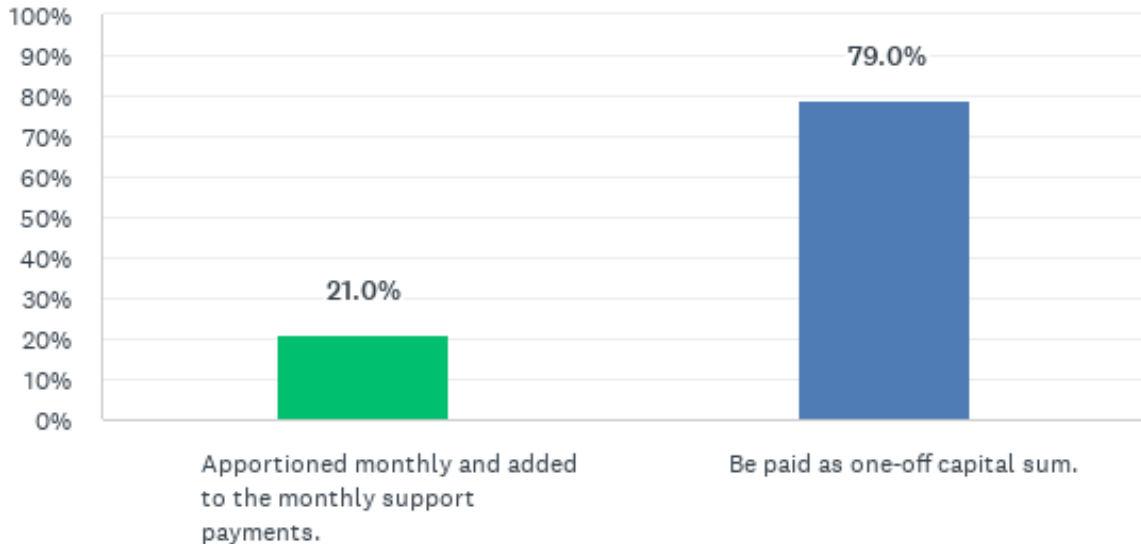
- *It's simple, the issue is who's going to pay and if it's going to be UK government, would they be willing to transfer a bunch of money to SIBSS or to Scottish Government to do that? That's going to be the issue there. The UK Treasury should pay simply because all this happened before Devolution. To try and foist the liability onto smaller devolved nations would be an injustice.*
- *The people here have spoken, over two thirds prefer the localised response. They trust the Scottish Government more than the UK Government, when it comes to speed and transparency.*

A questionnaire respondent gave an illustrative response to support his/her opinion:

- *Whitehall must not run the compensation scheme, for Scots it must be run from Edinburgh - I trust them more than the folks in distant Whitehall. We got parity payments pretty quick after it was announced and the Scottish Government were in the middle of an election too and they still managed to get the payments out to people. I heard the poor English folks are still waiting on a lot of parity payments - that's unbelievable that Whitehall would not make it an absolute priority for EIBSS to make the parity payments asap. What happens with Inheritance tax issues? Compensation should not affect income tax or benefit entitlement OR inheritance tax. I feel no matter what, the UK government will take it 'to the line' - I don't think they'll see the urgency in all this - we're all getting older - are they waiting for us all to die off? I don't think it'll be vast sums of compensation, but you never know. Matt Hancock said it was the biggest mistake in all NHS in all its history. Compensation should reflect that.*
-

Q8: If you are already in receipt of payments from support schemes, would you prefer any compensation to be added on a monthly basis to your existing monthly support payments, or would you prefer a one-off capital sum.

Answered: 257 Skipped: 1



ANSWER CHOICES	RESPONSES	
Apportioned monthly and added to the monthly support payments.	21.0%	54
Be paid as one-off capital sum.	79.0%	203
TOTAL		257

Roughly 4 times more people wanted lump sums than periodic payments (79% v's 21%).

One comment from a Focus Group summed up the result from their perspective:

- I think part of the rationale from the comments from that is that people are thinking ‘who knows what’s going to happen to me tomorrow?’ Say I die, my partner and family members are going to have a fight to get the rest of the balance of that cumulative monthly amount from the government. Whereas if it’s a lump sum, I’ve already got it, it’s in the Estate and they don’t have to fight for it or go through any more hoops.*

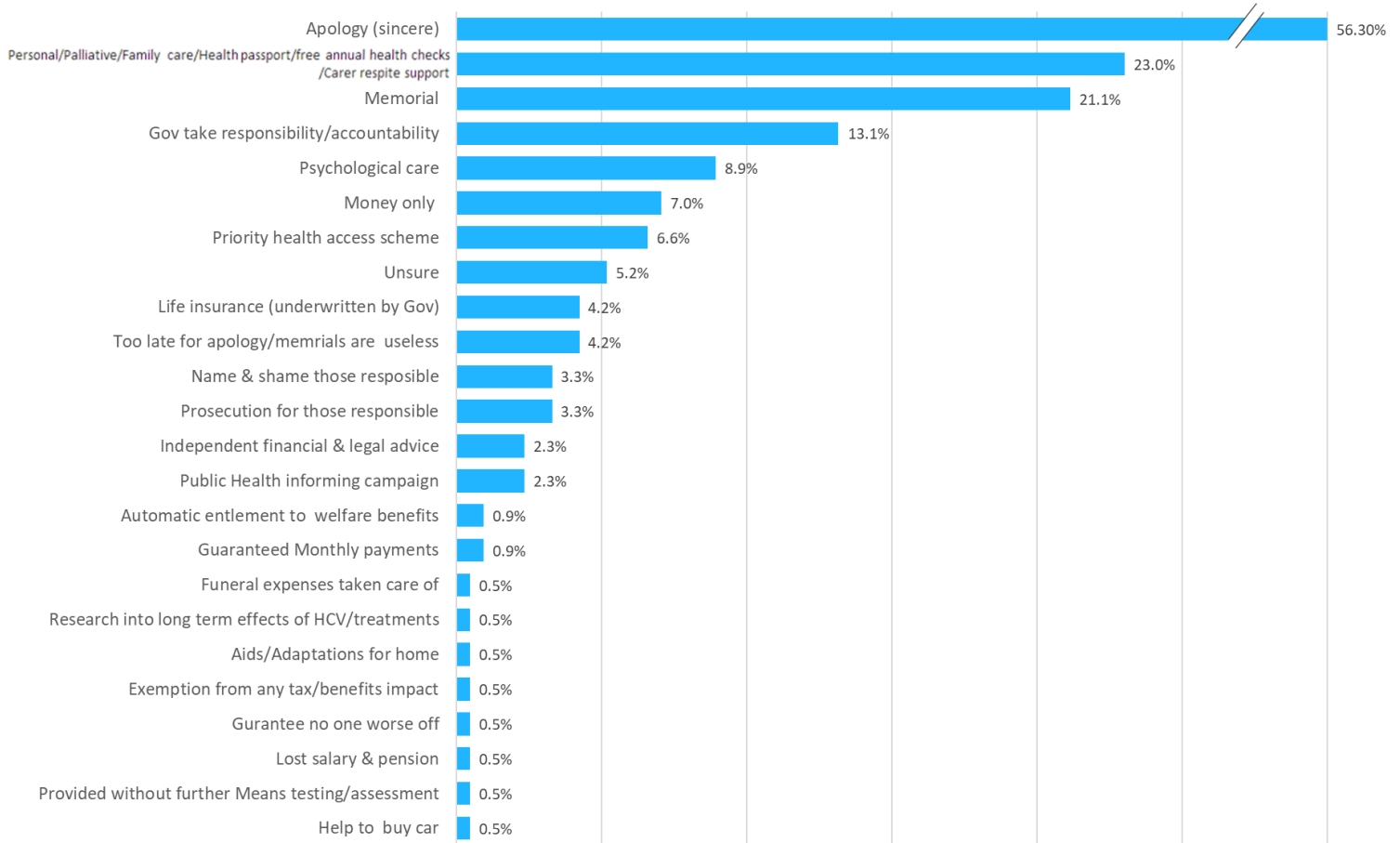
Q9: What other services would you regard as compensation other than financial payments e.g. personal care, an apology, memorials etc.

213 comments were made in response to this question. Many reiterated the 3 examples above. Many added other examples important to them.

All responses are shown in Appendix B.

These have been grouped and charted for illustrative purposes below:

What other services would you regard as compensation other than financial payments?

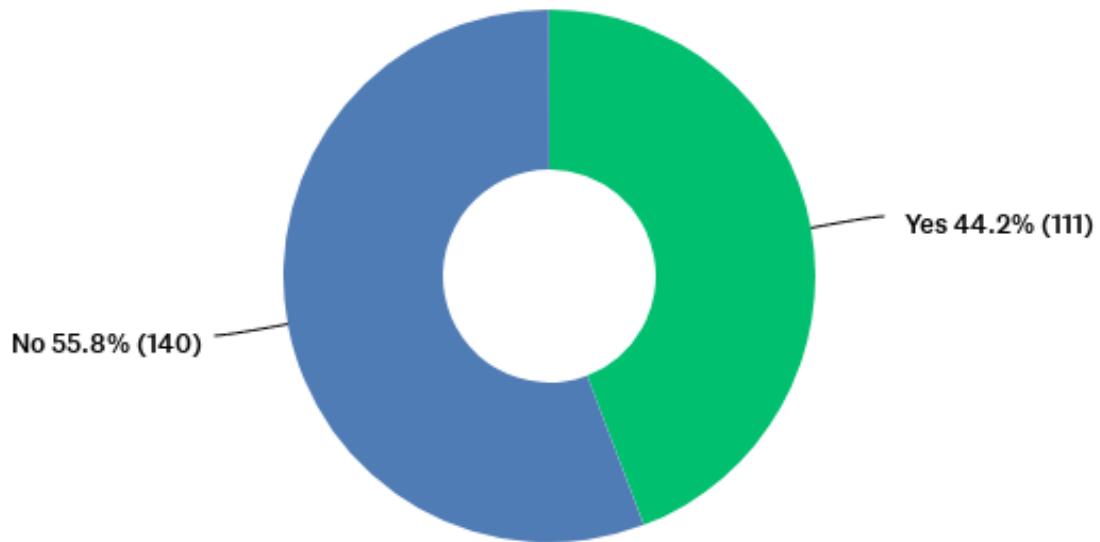


56.3% wanted a formal, sincere and meaningful apology. 21.1% wanted some type of formal memorial funded by UK Government and 13.1% wanted the UK Government to expressly take responsibility and accountability for what happened to the infected and affected victims.

Just under a third (31.9%) said personal care/priority health care provision and psychological care provision should be included in any compensation package.

Q10: Would you be willing to take part in a meeting with Sir Robert Francis in person?

Answered: 251 Skipped: 7



ANSWER CHOICES	RESPONSES	
Yes	44.2%	111
No	55.8%	140
TOTAL		251

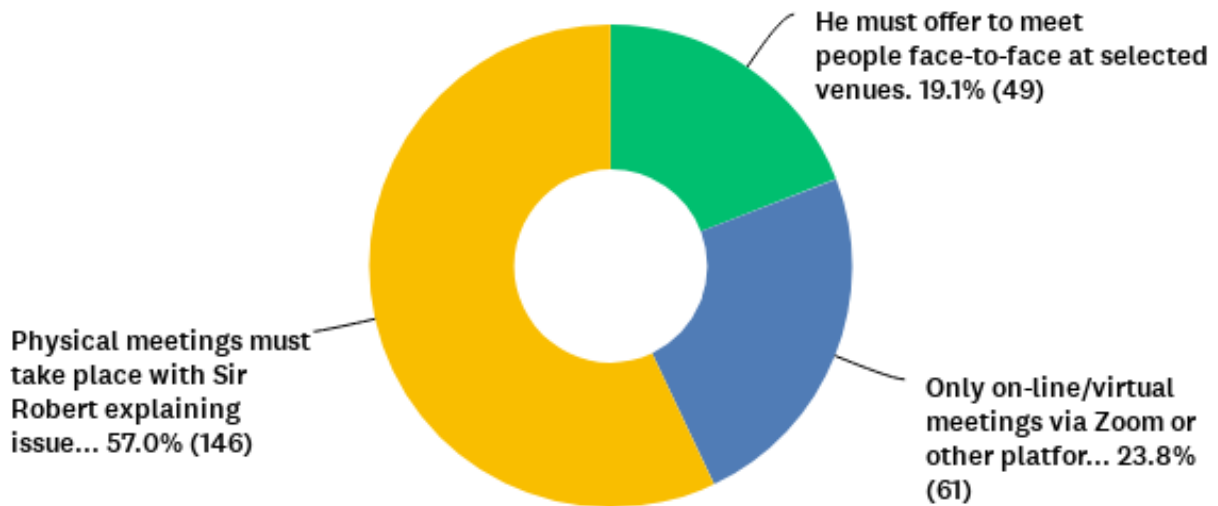
Most said no (55.8%), and the reasons cited included infirmity/age related issues restricting movement for people. Covid and winter viruses were also a factor for people who did not want to attend personally.

For those who did want a face to face meeting they said the consultation had to be meaningful, Sir Robert had to see the visceral effect on people through their own words and emotions. It was noted that the meeting for bereaved people was held after effectively only 1.5 days of notice and that the infected meeting was oversubscribed but limited to around 20 people.

At the time of writing it has been advised one further meeting has been scheduled to accommodate the level of demand.

Q11: Regardless of whether you can personally attend or not, do you think Sir Robert Francis must meet in person with the infected and affected community with regard to this compensation scheme consultation, or do you think a zoom or virtual meeting over the internet is sufficient?

Answered: 256 Skipped: 2

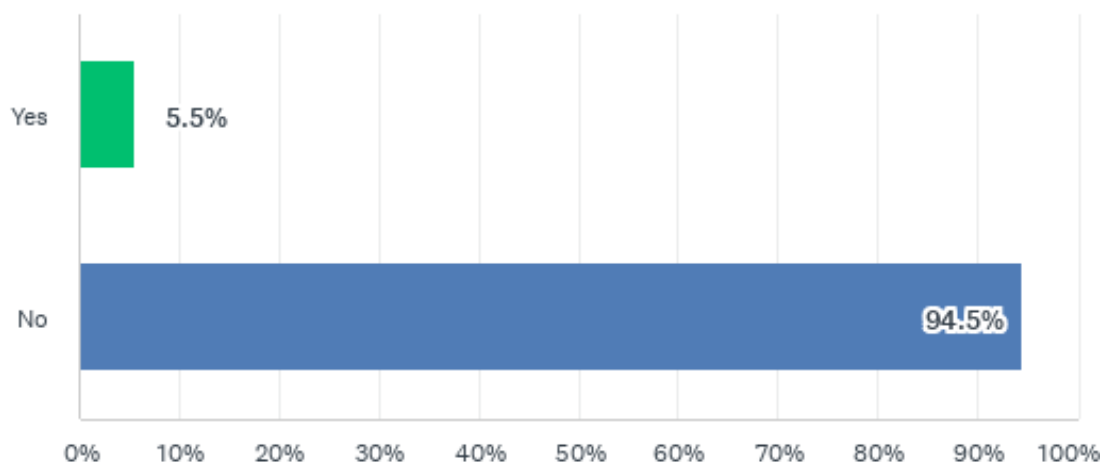


ANSWER CHOICES	RESPONSES	
He must offer to meet people face-to-face at selected venues.	19.1%	49
Only on-line/virtual meetings via Zoom or other platforms would be appropriate.	23.8%	61
Physical meetings must take place with Sir Robert explaining issues face to face and being able to take questions from the audience, AND these meetings should be able to be attended virtually via zoom etc. for those who cannot or are unable to attend personally accepting.	57.0%	146
TOTAL		256

57% wanted a person-to-person meeting with on-line accessibility too. Almost a quarter of people (23.8%) wanted online meetings only. Again, Covid is possibly a factor here as well as home-based convenience.

Q12: Some observers of the process believe there may be a possibility of previous payments received by infected and affected people being considered as compensation, or part-compensation. This might mean they could be treated as 'payments on account' and deducted from any newly designated compensation amount (Sir Robert Francis now calls it "Credit for past payments"). Should any payments you have received already, whether from the support schemes or Skipton/Caxton/MacFarlane for example, be treated as payments 'on account' of compensation or be deducted from any eventual compensation award?

Answered: 255 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	5.5%	14
No	94.5%	241
TOTAL		255

A resounding 94.5% say “No” to current and previous support/ex-gratia payments being treated, in any way, as part compensation or as payments on account of compensation. This question prompted a large response from respondents and Focus Group attendees:

- *Previous payments were never classified as compensation so should NOT be deducted from future payments, previous payments gave held us all in limbo with constant stress for years*
- *No deductions should be made for payments that have been drip fed over the years!*
- *We have went through decades of absolutely no money it’s only now we are starting to get what we should, no past payments should be considered.*

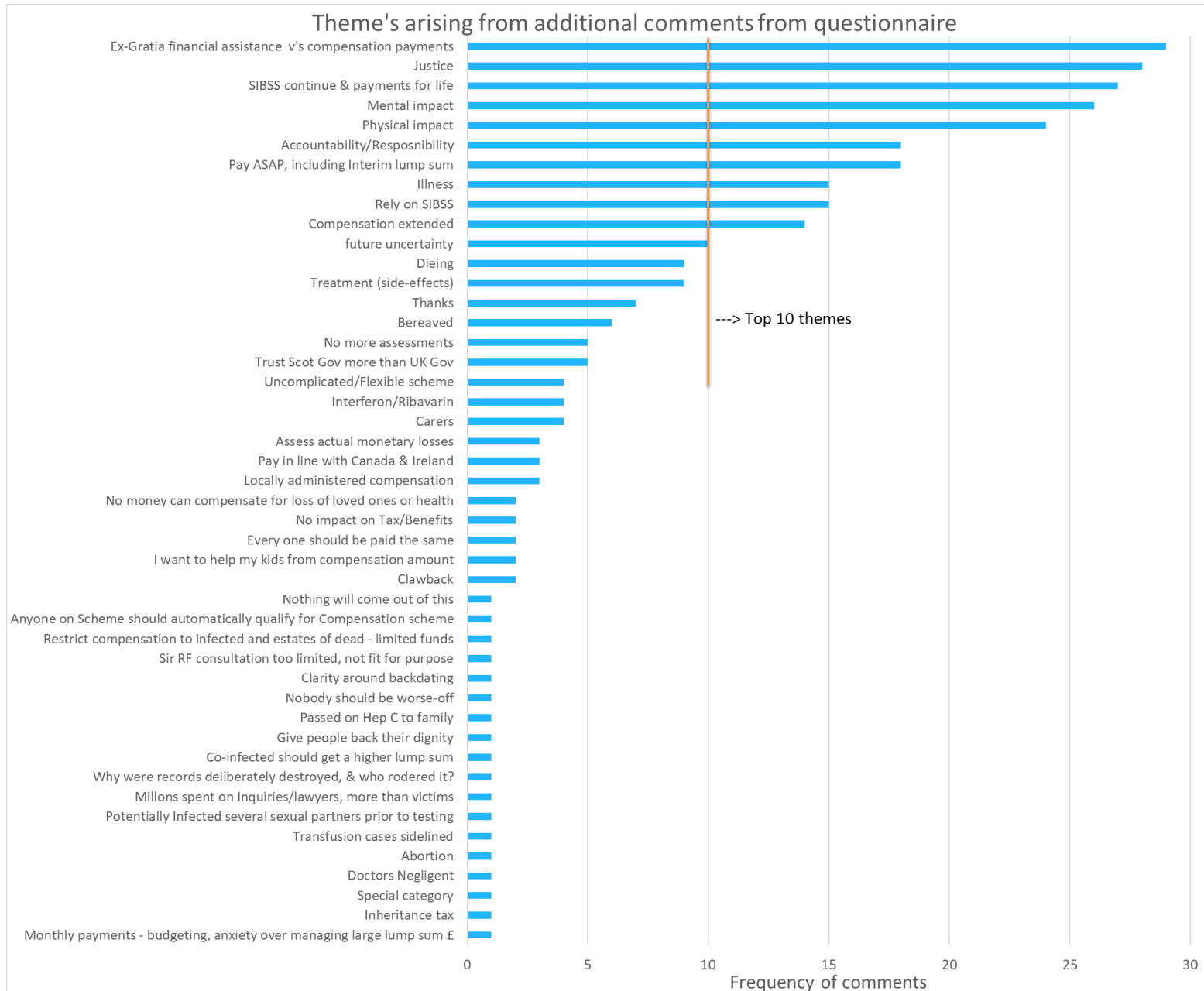
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- *Wife has cancer - from hep c - liver impacted now tummy cancer. No way should support payments be stopped or counted as poa for compensation. People are entitled, they shouldn't have to ask or be assessed yet again! We're all elderly, we're both 84...*
 - *Sounds like the future of the payments is uncertain which is a concern and has worried me in the past. It also sounds like there may well be some rowing back in the amounts awarded. I am of course, referring to "credit for past payments" paragraph above.*
 - *Previous payments should not be considered as it was not considered as compensation!*
 - *The reason I don't think any past payments should be deducted is because in the government own words these were not compensation payments and it is high time they stood up and show why we are called Great Britain and do the right thing by those infected not try and cover anything else up or penny pinch*
 - *Previous payments were NOT compensation!!!*
 - *Payments were no compensation and should not be considered compensation! Not one person should be worse-off as a result of any changes!*
 - *Payments already received, do not even come close to most of the compensation given by other countries with similar issues. As a haemophiliac, we were the "patient zeros" if you will, what was done to us cannot be undone. Anything less than what was awarded in the Irish settlement of tainted blood, would be completely unacceptable.*
 - *In response to question 12, I completely understand the logic behind it and with the current global economy being the way it is, even more so. However if this had come to pass in a much timelier manner, when the UK was better off, the issue would be viewed differently. And the tardiness and timing delay is not the blame of the recipients nor for the want of their trying. Secondly, current payments should not be counted morally or legally. People haven't been receiving compensation. That has been made very clear. Aid but not blame related compensation. No blame accepted how can compensation be deducted from aid paid previously which was clearly stated not compensation. Cart before horse. If current aid is compensation, then "culpability" should have been accepted back then. Shouldn't be allowed to have cake and eat it. Consider this appropriate punishment for all that had gone on before to the victims- denial after denial, deaths without truth being acknowledged, stigmatisation. The list goes on. You can't deduct compensation which was never paid. We merely received financial assistance.*
 - *Living with a potentially fatal virus day in day out has a devastating effect on a person's life. Frustration that I was knowingly given a deadly virus by health professionals in whom you put faith and trust is horrific, a death sentence imposed upon innocent people and the effect on their families should at the very least be heavily compensated. The whole*
-

suggestion that any previous payments be deducted is quite sickening.

- *They must not deduct payments and payments need to be paid now.*
 - *You can't tax or take any payments from us as they were paid out as ex- gratia money to help our living standard for life. The Government have not paid out any compensation or took responsibility for their actions and why are you going to tax or take money off infected and affected when it was the government that infected us in the first place.*
 - *If the previous ex Gratia payments were said and named as compensation then deductions could be argued but as it was ex Gratia I can't see how this could even be lawful.*
 - *On the last question, payments to date have been ex-gratia without acceptance of liability; they have been voluntary. It is not appropriate that these compensation payments should be deducted from any payments under the Sir Robert scheme.*
 - *I have asked Robert Francis to apply his legal expertise in seeking definitive clarity over the legality of counting ex-gratia payments as compensation.*
 - *If the Government insists that past payments are to be counted as compensation, then the Government will need to back-date their admission of liability to when the first scheme was set up. They can't have it both ways.*
-

Q13 Is there anything else you want to add that you think is important and should be included in the consultation exercise considerations?

Being so open-ended by design, this question also generated a great deal of material. Whilst Appendix C details all the responses, the following selected entries below have been highlighted here and broken down thematically. The chart below helps illustrate the strength of feeling across these themes:



Top 10 themes:**1. Conflation of ex-gratia payments and compensation to minimise compensation awards:**

(See selected comments shown in Question 12.)

2. Justice:

- *Governments cannot be allowed to shirk away like thieves in the night. Governments cannot be allowed to 'slide out of this'!*
 - *You had the trust of vulnerable people. This trust was abused and misplaced and must have a consequence for decision makers without protection or Crown immunity.*
 - *The fact that this atrocity was buried and hidden for decades speaks volumes about guilt! Otherwise, why hide circumstances? Why not 'spread the word' to save lives, as would have been the case in my husband's situation. How many lives could have been saved with this philosophy? Why the secrecy, deception and lack of truth? This could be described or assumed to be abusive behaviour.*
 - *We regarded other countries who are under strict governmental regimes and commit atrocities as cruel and unethical in their treatment of their subjects? I never considered that I would be forced to regard my own country, Great Britain, as anything other than caring responsibly for the health and well-being of its citizens. Trust, security, safety and health and well-being have surely got to be paramount for any caring government. Why then are we still waiting for answers? Are we any better than any regimes as described above? I think not. It may be considered by some unethical dehumanised politician to be easier to let them die, easier and cheaper. Are we then to eliminate anybody born with a condition or disability, which is requiring treatment by our health service? As a country, what does this make us? If we wish to be considered to be better than regimes run by despots and tyrants, then we need to make sure that no government or health service has the power to decide to deliver treatments which lead, or almost certainly, will lead to long, slow suffering and death.*
 - *I wonder how many of these people would feel watching a lovely six foot two young man waste away to a tiny, emaciated small body? This is the reality and result of irresponsible actions - devastating to those who were trying to save his life and those who loved him.*
 - *Whatever they give will never be enough for the lost and dying x*
 - *Please don't let us down. I was 23 years old when I was infected with contaminated blood. In those 40 years my health plummeted. I lost my own youth. My children's youth. My marriage. My career. Alongside I had to endure stigma. Ignorance. Discrimination.*
 - *This has been going on for 40 plus years, cost millions on various enquires, no one has been held accountable for this and the appropriate compensation has still not been awarded to those individuals and their families affected by this appalling travesty that has touched so many lives over the years.*
 - *Many people infected and affected have campaigned for close to 40 years seeking answers, an apology and recognition of what has happened to them. Sadly many people are no longer*
-

around to see their campaigning reach these final stages. And final stages it should be. The UK Government have a duty of care to the survivors and the families of those who have died. 40 years of mental anguish and detriment. Declining health, losing friends and family long before their time. The impact of this tragedy on 1000's of people who simply attended hospital seeking help and were left broken. Mentally broken. Financially broken. No amount of money will ever make that pain go away but whatever the final compensation model is, it must make amends for the horrendous treatment of the victims by politicians and clinicians who up until now haven't shown any genuine remorse or acceptance that things did go wrong that could have been prevented.

- *Hep C ruined my life and mum & dad's lives.*

3. SIBSS regular payments must continue:

- *Thanks for all the hard work that SIBSS are doing.*
- *The Scottish scheme must continue and my monthly payments must continue - I depend on them to have any semblance of a normal life (what's left).*
- *Compensation should be paid on top of/in addition to the SIBSS payments.*
- *The monthly payments have been life transforming for my family and I.*
- *Thanks for all the hard work that SIBSS are doing.*
- *Haemophiliacs should be treated as a separate group from the other victims. We were repeatedly infected and those in charge knew it was happening....but did little to stop it. The SIBSS payments, and those in the other home nations, should continue for life (as happens in Scotland) but should have no bearing whatsoever in the compensation amount awarded to recipients. Victims should receive compensation as soon as possible given the rate haemophiliacs are dying. A substantial 7-figure sum should be paid directly to them in the form of set compensation without assessments/reviews etc. if someone is already receiving SIBSS (or other IBSS payments) this should be sufficient evidence for compensation to be awarded asap.*
- *Existing payment MUST be increased every year by at least 5% above the rate of inflation.*
- *SIBSS have done very well, I'm grateful. Doesn't bring her back though. Helps a lot financially though. Thank you.*
- *If it wasn't for the monthly SIBSS payments I would not be able to live at a good standard of living. I have applied for a number of benefits and been declined each time.*
- *I believe there should be a seriously substantial lump sum paid which reflects the huge hardships, loss of life quality and emotional turmoil of all infected and affected, as well as ongoing monthly payments of at least £30,000 for life.*
- *I have really struggled financially my entire adult life until I got regular payments from SIBSS. I would be lost without them with no easy way to explain to benefits people (DWP) why I have extra money.*
- *The payments must continue and the scheme must continue.*

4. Psychological impact:

- *Shaking*
 - *Hep C ruined my life. Had childhood leukaemia and got Hep C from blood/plasma for that, at [redacted] hospital, then [redacted]. Had leukaemia in bone marrow. Got treated from 1986 to 1988, Born in 1971, my birthday is [redacted], [redacted]. Don't know how I'm alive still. Now scared of socialising, going out. Have arthritis, sciatica, back problems, can't go for walks in country like I used to. Getting severely impacted payments from SIBSS. They are a Lifeline. Had two bad experiences before with one psychiatrists saying I'm making it all up. Had traumatic experience at [redacted] Hospital. I self-harmed as child and into my early 20's. Can't walk much, get taxis to where I need to go. Dad helps a lot, he's 72 and drives me about places. He has his own health problems. Hep C took it out of mum & dad too, they've been through the mill with me. I have bad memory problems. Benefits/Job people think I'm 'at it' and don't believe me. SIBSS payment is a lifeline. Hep C ruined my life and mum & dad's lives, was bad enough beating leukaemia but Hep C is worse. It's changed my 'head' over the years. I've not had a relationship with a woman for over 15 years - can't bring myself to tell women/people about Hep C. (Note respondent broke down half way through the telephone survey).*
 - *Was put under the table for too long and stigma sticks and everyone is left to deal with this every living day of their life and must continue on in family's life after losing someone.*
 - *Unless you have lived with the true impact of what this means to a family you will never understand. No amount of money can compensate for the overall impact and effect it has short and long term.*
 - *Many people, like myself, were only told of our infection as teenagers, were also told our life expectancy wasn't great. As a teenager, being told you are going to die is not a motivator to start planning your career. It effectively derails us from the start, and this must be recognised in my opinion.*
 - *I am not very good at speaking and talking about my situation in public I get very anxious even filling in survey has made me anxious as not sure I've ticked correct boxes.*
 - *I just want this to end. I want to be able to get on with my life and start rebuilding it.*
 - *Totally against personal assessments as I've been assessed often enough regarding my health problems with Hepatitis-C. It affects my Mental Health these assessments make me feel as if it's my fault it's only recently that we are treated with a bit more Respect from the DWP assessments. These assessments of Victims Of The Contaminated Blood should be stopped immediately. As they are affecting my health.*
 - *I have said that meetings with Sir Robert should be face to face but also said I would be unable to do this myself. This is because of how this has affected me and am sorry I don't have the courage to do this myself but hope other who can will be able to do this.*
 - *Any revised compensation scheme should account for the psychological impacts of the consequences of receiving infected blood products & not just the physical impacts.*
 - *What value can you put on being poisoned, not knowing for 23 years and then being lied to about it for decades?*
-

5. Physical impact

- *40 yrs compensation - what is it for 40 years of my life. How can you estimate it, they've destroyed my life, can't put number on a life.*
 - *The impact that receiving contaminated blood may have had an impact that can't be determined or understood.*
 - *I have autoimmune HCV and the drugs I'm on have many side-effects. I was also put on interferon & ribavirin which was absolutely horrendous - I was bed ridden for 6 months. There's been a cancer link to that treatment regime. I've since had bowel cancer. I know others have had cancers too linked to the interferon/ribavirin.*
 - *I was infected either in 1969 or 1972 through blood transfusion after giving birth at [redacted] Hospital. Wasn't told I had Hep C until I gave blood in 1995 - 23 years after infection. I had felt unwell for years before 1995 and doctors couldn't figure out why. Was horrendous, it impacted my whole family, my son & daughter had to be tested regularly. Had interferon, took for 6 months and that was horrendous, it wasn't successful and I could only manage 6 months and it had a seriously bad effect on my health - physical and mental/emotionally. I got new treatment 2 years ago and have cleared virus, but damage has been done on so many levels. I am checked up on every 6 months now. I am on SIBSS and getting the severe impact payment ... I don't know how much I should get in compensation - how much is a life worth?? What value can you put on health?*
 - *I WAS INFECTED IN 1983 AND ONLY RECALLED IN 2016, WHY DID THE NHS NOT RECAL ME BEFORE THEN, I HAD TO HAVE AN OPERATION ON MY STOMACH IN 1984 AS I WAS CRONICALY SICK AFTER MY 1983 BLOOD TRANSFUSION and suffered for 35 years.*
 - *I have an infected liver and I don't know the long term consequences to my life.*
 - *My father contracted leukaemia when he was 32, and received many plasma and blood transfusions. One was tainted and he was infected with Hepatitis C. This affected his whole life. He survived the leukaemia and lived for another 30 years, but always lived in shame as he was ashamed of having hepatitis c. It affected his health in so many ways and he had to make so many adjustments, which affected our family life and the things he was able to do. He was always so scared of giving it to my mum or I, and was so ashamed of his condition as he thought people would think he was a drug user, so he would never let people know of his condition. His liver was badly affected, and that meant his quality of life was substantially reduced, and therefore quality family time was hard sometimes. He died in 2016, after having treatment to try and cure the Hep C, which actually affected his lungs adversely and he unfortunately never recovered. My children were small and they now are missing out on the opportunity of growing up knowing their grandfather.*
 - *I know we are going through a huge health crisis at the moment, however the people who were infected with blood products should never be forgotten. My father died prematurely due to complete negligence of those responsible for safe blood transfusions in Scotland and the UK. Every family celebration he has missed cuts the family deeply, he was the most wonderful, kind, generous spirited father, anyone could hope for...*
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6. Accountability and responsibility:

- *I find it difficult to describe the depth of pain inflicted on me and my daughters at the untimely death of my husband, their father. The initial extreme distress mutates to an unimaginable depth of mental agony as the years have gone by, with no acknowledgement or responsibility taken by those responsible. Tortuous and unending. There is no serenity or peace.*
 - *There is also no understanding the depth of depravity which would drive any individual, medical or otherwise, to repeatedly inject someone with a product which was more dangerous than the condition which required it.*
 - *My answers/comments for Kenneth Clarke: It is quite obvious that you have risen to the level of your incompetence and sunk to the depths of your depravity. You are a fine example of a man's inhumanity to man. Denial of knowledge and ineptitude in the performance of the person in the position of Health Minister is inexcusable. Pomposity as an ineffective cover up and inevitably indicates lack of empathy and humanity. Is the title of Minister of Health merely that? Just a title without responsibility?
How dare you demean the pain and loss suffered by those infected and affected? It seems obvious that you have no human feelings, merely superficial characteristics of humanity. Maybe the ministerial title for you, Mr. Clarke, should have been a Monster for Health!*
 - *Does the Hippocratic Oath no longer apply? It cannot be bent/manipulated to suit governments.*
 - *Dishonour, dishonesty, disgraceful. Shame on you.*
 - *To sum up, the best that I can say is that you have failed drastically and completely and cutting-out your duty of care!*
 - *The alternative can only be that you deliberately ignored and carried out treatments which you knew could be harmful, destructive or possibly fatal to those who require to help. Unfortunately, honesty is a foreign concept to many people in those positions.*
 - *Governments cannot be allowed to shirk away like thieves in the night? Governments cannot be allowed to 'slide out of this'!*
 - *You had the trust of vulnerable people. This trust was unused and misplaced and must have a consequence for decision makers without protection or Crown immunity.*
-

7. Pay compensation ASAP and interim lump-sum:

- *Being given infected blood has impacted greatly on a lot of people's lives, including my own, and so it is important that we are compensated for this. Other countries have paid compensation so I don't see why we are so far behind.*
 - *The Inquiry is proceeding more slowly because of Covid which means that any compensation will be delayed. If the Inquiry will report much later because of Covid. An interim report (if culpability is found) would hasten the compensation process. We are all getting older and many have life-shortening health issues. We all seek closure.*
 - *This has been going on for 40 plus years, cost millions on various enquires, no one has been held accountable for this and the appropriate compensation has still not been awarded to those individuals and their families affected by this appalling travesty that has touched so many lives over the years.*
 - *I've never been able to get a mortgage and am still paying rent at 61 years of age and have nothing to leave my children*
 - *Lives are on hold due to the ongoing damage to all those affected. It is important that compensation be provided as soon as possible to allow people to utilise sums immediately. Further the monthly scheme should continue indefinitely as people's circumstances are varied and many are reliant on the payments to stay afloat in the quest of a somewhat "normal" life. Further, family members including spouses should be provided for as they bear the brunt of caring and supporting those affected by infected blood. Recognition and payment should extend to them too for the vital and invaluable support they provide.*
 - *This process must be consolidated soon.*
 - *People are dying at accelerated rates now and it will not get any better going forward. Compensation must be paid as soon as possible. Part payment now would be better... stop the delays.*
 - *A part payment of the compensation we're due should be paid now. No more delays!*
 - *I agree, decent interim lump sum compensation awards should be paid now. And by decent I mean anything over £100K.*
 - *The only problem for Government with making big lump sums is that it is a big initial outlay from budgets, while accountants might prefer a budget projection with set amounts over a longer period.*
-

8. Illness:

- *It is important to fully understand the impact HepC possibly has had/is having on people's life's span.*
- *My father might not live to see conclusions.*
- *I'm older (79 now) and got infection in 1989 and it took 17 years to get diagnosed (2006) I lost my husband a short time ago and I'm lucky to be here & some others haven't been so fortunate.*
- *The impact of me contracting Hep C via infected blood and passing on to my family has sadly been huge with ongoing negative consequences.*
- *These assessments of Victims Of The Contaminated Blood should be stopped immediately. As they are affecting my health.*
- *I'm living with side effects of meds for autoimmune HCV and have done for the past 15 years.*

9. SIBSS payments relied upon as a life-line:

- *SIBSS payments have been an amazing lifeline. Phoned SIBSS up to thank them and was crying on phone, woman at other end was crying with me.*
- *I'm English and was infected in Scotland. I'm grateful to SIBSS and Scots for support I get. Very difficult at start... Husband died in 1989, lived in north east Scotland, now live in north east England. Can't say thank you enough to people in Scotland who've helped us - a life-line - thank you.*
- *I am on SIBSS and getting the severe impact payment. SIBSS is a lifeline to me.*
- *I have really struggled financially my entire adult life until I got regular payments from SIBSS. I would be lost without them with no easy way to explain to benefits people why I have extra money.*

10. Compensation categories extended

- *The equality for all is already unfair for those that have died. This has damaged generations. Compensation should be a given with as much past and present families.*
 - *I think that it's really important that parents and children receive compensation in their own right.*
 - *Lots of parents have sacrificed their entire lives and careers looking after vulnerable disabled children with infected blood I believe they should be compensated as well.*
 - *It is very difficult for carers to talk about their experiences in front of those infected because they do not seek to inspire guilt on loved ones who have suffered almost*
-

unspeakably. From an individual perspective, caring for those rendered sick amounts to the definition of modern slavery. We were prisoners of love, and when our loved ones sought to end their suffering, treated like a jailor.

- *It is often the case that the carer's life is entirely dominated by the needs of their loved one. Caring is a selfless act. I have heard it often said that the carer becomes a non-person, and invisible.*
 - *It remains to be seen if the eventual framework reflects and considers the full scope and impact on the deceased, bereaved, the affected and specifically carers.*
 - *Compensation should be paid to deceased estates.*
 - *People should be treated FAIRLY, and EQUALLY. Within a tariff system, everyone in a particular category gets the same (fully commensurate amount for that damage), but that does not need to mean all tariffs are valued the same.*
 - *People should not be limited in their expectations by a top-down approach with a set budget to be sliced up between people, thus forcing them to be in competition with each other, i.e. "divide and conquer", or "I'm more deserving than you."*
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7 Conclusion

A picture of the situation

One of the by-products of this compensation consultation exercise was that a picture has been painted (as an overall summary) of the situation faced by people who were infected in Scotland by life changing and life limiting viruses due to receiving contaminated blood or blood products as part of their NHS treatment. It is clear that the respondents and attendees foresee as entirely justifiable the need for substantial compensatory amounts commensurate with the detriments suffered. From the very honest and often heart-felt responses to the consultation by those who took the time to contribute, the following picture has been formed.

- The picture in Scotland is of people responding to their viral infections, or the infections of their family members, in a variety of ways. Emotions go from anger and outrage, through to despair and resignation. It is fair to say that in the majority of cases people are, at least, dissatisfied by the circumstances that led to their becoming infected, by the ways they found out about their viral status, by the perceived downplaying of the seriousness of the situation, and by the apparent lack of anyone taking responsibility. Many have lost trust (perhaps irreconcilably) in the medical profession who they see as having used them as non-consenting guinea pigs or as the purveyors of a life-limiting illness. This creates a relationship dissonance in the patient/practitioner context where normally the one relies on the other to put forth their best efforts to secure the best outcome for them. Many have also lost trust in governments who they see as wringing their hands or conspiring to place delay after delay in the path of getting to the truth. People see their NHS as trying to hide from past mistakes despite the “do no harm” mantra. They see government as trying to dodge the prospect of supporting this distinct group of people - whose infection came about through no fault of their own - in case it costs them money, and/or in case individuals are called to account. The strength of feeling may not always be justified in every instance, but from their perspective the delays, the misinformation (or lack of information), the loss of records and other key paperwork, the apparent strain between safety and savings considerations, along with all the other matters raised by respondents, have conflated to create a group of people who have become mobilised and determined to see some kind of just outcome, especially with regards to compensation and continued financial supports.
- The picture is one where infected people’s lives, and those of families, carers and in particular the bereaved, have been impacted on in a host of ways, none of them positively. In terms of health and wellbeing there seems to have been a quite devastating result for some people as their worlds “turned upside down” from ordinary, happy, fulfilling lives, to situations of fear, uncertainty for the future, greatly reduced quality of life, and a range of diverse health detriments. For those who have “cleared the virus”, and who appear to have journeyed through what was for them a temporary “blip”, they may wonder at the “fuss” others are making. This difference in experiences is perhaps a key aspect which lies at the heart of the problem with HCV infection. There are different genotypes with different levels of responsiveness, different timescales for negative impacts (if any), different side-effects with different degrees of severity, different coping abilities and resilience capacities, and even at the individual patient level different days can be much better or much worse than the next. And of course, a significant number of people have died which, while it might

conclusively resolve the problem for the “infected”, it does not relieve the pain felt by the “affected” who remain.

- For many, HCV infection is a kind of “double jeopardy”; their costs just to live go up (insurances; mortgages; heating; care needs; etc.) at the very time when their capacity to be economically self-sustaining go down (reduced capacity to work, sometimes completely; the need to downsize housing and standards of living; eating into savings; etc.). However, many infected/affected people seem to want to avoid the appearance that they might be involved in campaigning just because there is the possibility of compensation in the future, and/or ongoing “ex-gratia” payments (however derisory these may be). It feels undignified to be “in it for what they can get”. Of course others have unashamedly called for fair and realistic compensation for what they claim to be genuine losses.
- One respondent recalled how another infected person, who had a financial services background, had carried out an exercise to work out how much his HCV infection had cost him, purely financially. This included various parameters such as being off work for periods of time and so missing out on overtime, and being held back for promotion due to health issues with the concomitant losses through years of unrealised promotion. The amount was certainly greater than any SIBSS pay-out. People know that they have been financially disadvantaged, and not by their own actions but by the state through one of its key public services. In terms of the picture, most of the responses to this compensation consultation only briefly sketched out the costs associated with living with viruses as a recipient of contaminated blood or as a family member. It is understood that the financial implications cut across many different aspects of everyday life. For example, unemployed people and those not able to work (who together form the largest grouping of participating HCV infected people), pay more for car insurance just because they don’t work. The full costs of living with HCV from contaminated blood have never fully been calculated, and this may be a gap to be filled. (Such an assessment would have to include not just loss of earning potential, but all the quality of life cost factors that can be assigned an economic value using various assessment models and tools⁴ in the form of a social audit or an injuries calculator⁵). Affected people know that while money does not bring back full health (and certainly not a deceased relative), lack of money is a major issue for many infected/affected people, in the most practical terms.

So in summary, the picture in Scotland for those whose HCV infection arose from contaminated blood is one of distrust, disempowerment, emotional turmoil, personal and family tragedy, significant chronic health impairment and serious economic disadvantage. The sense is that for over 40 years the financial and other consequences have only been felt in one direction.

Unique issues

As mentioned previously there was an initial need to bring together contaminated blood Scottish infectees (mainly Scottish) for the purposes of collectively responding to the Compensation Framework Study from the specifically Scottish perspective. The need for this targeting expanded given the context of infections in Scotland, the particular aspects of Scot’s Law (including in relation to damages), and the differences as a result of devolved administration of the support schemes. This

⁴ For example, www.ilcuk.org.uk/files/pdf_pdf_129.pdf

⁴ Ogden tables: actuarial compensation tables for injury and death - GOV.UK (www.gov.uk)

bears a similarity to the matter of the route of infection. In order to focus exclusively on the needs of the designated cohort of infected persons, a level of emphasis has been placed on the distinction between people who have been infected with HIV, HCV and other viruses through a contaminated blood route and those whose infection has resulted from other circumstances. These other infection circumstances, which are more widely known in the public conscious, may include what has been loosely referred to as lifestyle behaviours or choices. This distinction has resulted in the identification of the contaminated blood cohort as having certain unique characteristics. Clearly once someone is infected and is at either at a chronic or acute stage of liver damage (and the largely ignored extra-hepatic consequences) there are mostly indistinguishable commonalities to the way the infection acts on the body. Similarly, the side effects of anti-viral treatment do not respect the means or route that caused the initial infection. This is generally understood, although in some cases there are apparent differences. For example, most HCV infected people who also had haemophilia were most commonly genotype 1. And genotype 1 people were, statistically, significantly less responsive to anti-viral treatment than other genotypes.

The commonly experienced health-related issues for people living with State-derived damages (including those related to people undergoing anti-viral treatment with its own exacerbating set of side-effects) have already been listed in this report and include: tiredness and fatigue; mental health problems such as depression; aches and pains (the “flu-like symptoms”); and a diverse range of specific deleterious conditions such as hepatic encephalopathy.

It is likely that many of the other dis-benefits are felt by the whole infected community beyond those who are State-infected, and these include, economic and employability impacts, social/relationship factors, increased insurance, and mortgage costs, etc.

However, from the responses to the Compensation Consultation it seems reasonable to draw out certain unique issues for the contaminated blood cohort of infectees and affectees which sets them apart from compensation claimants arising from other scandals.

“An unprecedented disaster requires an unprecedented response”

During the Focus Group element of the consultation it was stated that “an unprecedented disaster requires an unprecedented response”.

Nothing like this has happened in the UK before. In 2010, the Department of Health (UK) estimated that, for the period 1970 to 1991, 32,718 people in the UK were infected with hepatitis C by contaminated blood and/or blood products⁵. Most were from transfusions (by a factor of 6 times). Most are dead. It was no overstatement by Professor Robert Winston when he famously described it as “the worst treatment disaster in the history of the NHS”. That statement in itself, which has been quoted by numerous political leaders including Prime Ministers, lends this victim cohort a special status among victim groups. But that is not to diminish the tragedies of Hillsborough, Grenfell, Mid-Staffs, Windrush, etc.

⁵ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215828/dh_125977.pdf, Annex 2

<https://www.gov.uk/government/publications/review-of-the-support-available-to-individuals-infected-with-hepatitis-c-and-or-hiv-by-nhs-supplied-blood-transfusions-or-blood-products-and-their-dependants> (published 10 January 2011)

The Contaminated Blood Scandal is a grotesque human tragedy not limited to the UK, but is a global disaster which starkly reflected pharmaceutical interests' globalised business activities. Prosecutions have happened in other countries. Nothing of the like happened in the UK.

The Scottish Government announced its Public Inquiry, the Penrose Inquiry, only after it lost a judicial review. The UK Government only announced the Infected Blood Inquiry after mounting cross party consensus put pressure on weak leadership with the very real prospect of a defeat in the Commons. The establishment of financial support schemes was taken forward more on the back of these pressures, not out of the moral responsibility now firmly established by the Health Ministers of the four nations.

And all of that would not have happened as it did if it wasn't for the dedicated and selfless work of hundreds of campaigners and campaigning groups and charities throughout the UK.

Those who have survived are left broken and damaged by the virus(es) and the historic treatments the NHS gave them.

The harms are unprecedented and unique. They include:

- Cover-up and concealment, denial, deception and compounding detriments
- Stigmatisation, ostracisation and social pariah-hood
- Experiencing a more pronounced shift from prior economic independence to one of benefit dependence and grinding poverty
- Sense of loss of control, helplessness, and hopelessness
- Unresolved feelings of (sometimes gross) unfairness and injustice resulting in anger, frustration, etc.
- Sense of isolation, imposed loneliness, being a valueless burden on society
- Lack of support structures, including limited funding of the few peer support charities of the means of helping others
- Diminished trust in the health care profession
- Unbearable losses, including the destruction of intimate partnerships and family life
- Unbearable guilt at having been party to infecting loved ones, at aborting babies, at living a lie for decades, at not being more questioning of clinicians
- Suicides, PTSD, deep depression, mental illness, self-destructive behaviour, threatening behaviour towards others, and so much more.

Taking just a few of these to further explore uniqueness, as follows.

Unique Issue - Cover-up and concealment, denial, deception and compounding detriments:

- The history of the disaster is plagued not just by the deaths and illnesses of thousands but also can be played through avoidance of responsibility and lack of acknowledgement of the
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harms done and by whom. The Infected Blood Inquiry has recently shone a light on historic misdeeds and allegations of cover-up and concealment, denial, deception and detriment. For example, the scale of missing or destroyed records and the allegations of a concerted orchestrated effort to destroy paper-trails potentially reflects those acting on behalf of the guilty protecting their interests. But it also stopped many victims and their families from being able to substantiate their claims of infection route (for example blood transfusion infectees), and thus stopping them from being able to claim past and current ex-gratia payments and other financial support.

Unique Issue - Stigmatisation:

- Without seeking to appear judgemental or condemnatory, people whose HCV infection came about through treatment with contaminated blood often feel uncomfortable about being associated with, for example, Hepatitis C due to the prevailing public perception that it is a condition caused by drug misuse or unsafe sexual activity (regardless of how accurate an assessment that is). Infected people are aware of others who see Hepatitis and HIV, as “dirty”, and to be avoided to the extent that it can cause people to physically withdraw or at least lean away (perhaps unconsciously) if they find themselves in the presence of someone with such conditions. There are understood to be instances when Hepatitis or HIV is referred to in the context of a joke or flippant remark such that the person having the virus is somehow unclean or requiring to be treated with additional hygiene practices.

Unique Issue - Experiencing a more pronounced shift from prior economic independence to one of benefit dependence:

- This refers to the extended periods of time before infected people received regular payments from SIBSS. As has been mentioned earlier, viral infection from NHS treatment is not selective in terms of who has been afflicted. The target group for this consultation includes those from many different walks of life, including professional and academic people and others from higher socio-economic sectors. As before, with the need to avoid prejudice and stereotyping whole groups of people, studies do show that 90% of HCV infection in Scotland is directly related to illegal drug use and that this group is most likely to come from the poorest sections of society. Only 0.9% of HCV infection is attributed to contaminated blood product treatments, and only 3% from a group that includes blood transfusion cases (but this group also includes other infection routes). Put bluntly, those people infected through contaminated blood are proportionately more likely to be in employment and economically independent at the time of infection; and therefore they have more to lose. Indeed they have lost more.

Unique Issue - Sense of loss of control:

- Some people involved in this consultation have been living with Hepatitis and HIV for over 40 years. This would certainly qualify as a long-term condition. Of course those with a bleeding disorder would doubly fit the criteria. One of the more recognised issues for people living with a long-term condition can be a sense of loss of control. Whereas most people who become ill can simply go to their doctor, get a pill and recover, the same prognosis cannot be
-

offered to someone with a chronic illness. For those whose infections came about through a blood transfusion and who previously fitted into the world of illness/treatment/recovery, then coming to terms with their new status can be very challenging. It is sobering to contemplate that you are walking about with a life-threatening condition (which some have referred to as being like having a “ticking time-bomb inside you”) and you are not guaranteed to overcome it. This type of realisation can seriously affect a person’s state of mental health, which then can worsen their physical health. Emotional and psychological issues such as the sense of loss of control were widely expressed in the responses and the Focus Group discussions. There is already a case of a person in Scotland who underwent the new DAA treatment having not responded by the time of the second test.

Unique Issue - Unresolved feelings of (sometimes gross) unfairness and injustice resulting in anger, frustration, etc.:

- It is clear from the qualitative (i.e. written or typed in) responses proffered by many people who completed the questionnaire, that there is still a great deal of pent-up frustration, resentment and even rage at what they have had to go through. These so-called negative emotions are understood to physically affect the person who is feeling these responses by causing digestive problems, muscle cramps and other issues. There can also be psychological consequences such as a hardening of attitudes to life in general and the adoption of a “victim mentality”. The community of affected people recognise that there have been incidents of threats of violence toward medical practitioners which has resulted in the withdrawal of care for individuals. There is a cynical perspective among some, particularly those who have been active in campaigning over many years, that the medical and government establishment are “biding their time” until the ones making the loudest noise grow too old or just get worn down and give up. Regardless of whether there is any truth whatsoever in such assertions, to get to such a point where these thoughts can be considered credible is unhealthy and even toxic, not least for the people caught up in the emotional tumult. For others whose infection came about not by contaminated blood, there are no such unresolved feelings being levelled at the medical establishment. For some contaminated blood infectees it is almost a case of needing a healthcare version of a “peace and reconciliation” approach.

Unique Issue - Sense of isolation:

- In the case of contaminated blood infectees, it is particularly noticeable that those whose infection was as a result of a blood transfusion can be left feeling that they are the only person in the world facing their new and perhaps to them mysterious condition. Those from the bleeding disorder community at least had an existing support group, such as Haemophilia Scotland (or its precursory body) if they chose to avail themselves of its services. But even within the haemophilia group, because the numbers are so few and people are scattered across Scotland, these too, like the blood transfusion infected people, may not be able to escape the sense of largely being left to face their infection and its effects on their own. For those other infected people (i.e. not caused by contaminated blood) there do appear to be at least the offer of issues-based group-work programmes and other lifestyle changing support activities that build up a sense of togetherness and collective identity among them. As with

the other unique features for this virally compromised community, the sense of isolation can lead to further issues that impact negatively on overall wellbeing.

Unique Issue - Lack of support structures:

- Following on from the previous unique issue, and again in recognition that the total number of people understood to be within the hepatitis HCV contaminated blood cohort is small (under 550 people across the whole of Scotland - appendix E), then the opportunities to provide a comprehensive support network are greatly curtailed. As before, this is particularly challenging for the blood transfusion infected people. It is true that some services do exist, mainly in urban areas within the cities, but they usually attract persons whose infection was not due to contaminated blood. Of course that bigger cohort has needs which should be met, especially as people are trying to make major changes to their lives, but the support environment may not be suitable for everyone. Attempts by contaminated blood infected people to engage with supports that are open to the wider hepatitis C virus infected population tend to report a largely negative experience due to not really fitting in or having much in common with other attendees; for example if the issue-based group discussion is on needle exchange programmes or safer sexual practices. This issue of support structures/provision may be a challenge requiring the few providers from the voluntary and community sector to collaborate with government to find creative ways of effectively and efficiently addressing this unique need. Both Scottish charities have had to rely on significant volunteer and pro-bono work inputs in an effort to continue to support their infected and affected memberships. This position cannot be sustained.

Unique Issue - Diminished trust in the health care profession:

- This is another unique feature of their viral infection for the Scottish consultation cohort. For the bleeding disorder community it would be common for a cordial and familiar relationship to exist between patients and practitioners, particularly in the Comprehensive Care Centres. And even for blood transfusion infected people there was the general sense that “doctor knows best”. While the writer is not seeking to undermine this rather traditional view, it nevertheless remains that the label of the “worst treatment disaster in the history of the NHS” has been attached to the contaminated blood tragedy (beyond Thalidomide or other high profile examples). The erosion of trust has been acutely felt by bleeding disorder people. Even after the contaminated blood issue became known, they continued to be treated by the same doctors who may have been implicated in their infection. When it came to obtaining medical confirmation for the purposes of, say the Skipton Fund, again it was the same doctors who were being asked to sign-off the documents. And as the Penrose Inquiry, then the Infected Blood Inquiry, progressed and the transcripts of witness testimonies by clinicians were made available, their patients, the infected people, could read these testimonies and on occasion take issue with what was being given as fact to the Inquiries. This very issue has been significant throughout the UK Infected Blood Inquiry, where some Focus Group attendees stated that certain clinician witnesses were effectively calling the patient victim witnesses liars. This highlights yet another unique dimension to the contaminated blood narrative.

Unique Issue - Comorbidity:

- The various effects that people may face as they live with HCV infection have been listed previously. Some of these effects take hold and become additional long-term conditions in themselves. This can produce a multiplying effect on the impacts being felt by a person. Add to this the prospect of different drug treatments being prescribed for every individual condition, with each having their own set of side-effects, then the issue of comorbidity adds a further layer of complexity to the management of a person's health. For example, HCV infection is often cited as causing the patient to suffer from fatigue (to varying degrees). HCV anti-viral treatment is also known to result in fatigue-like symptoms (reportedly to a much greater extent), thus potentially exacerbating the pre-existing problem. One of the recognised possible long-term consequences of anti-viral therapy is the development of hypothyroidism in the patient. This also can commonly result in tiredness and fatigue. Thus it cannot come as a surprise when someone in this situation (which is not hypothetical), who is facing this cocktail of health disorders, has an up-hill struggle to function day-to-day. This multiplication of symptoms throws up a further unique issue to be tackled when it comes to responding to anti-viral treatment and support. And beyond the compounding of health detriments, there is the compounding of issues arising from the scandal itself. It is bad enough to have to continuously fight for paltry state benefits from the very State that caused you to need to depend on them, but add to that the assessments, the insurance refusals, the job rejections, the significantly reduced social status and sense of purpose, the feelings of worthlessness, the waste of an education, talent, and potential; to name but a few. These also add up to a set of perfect-storm circumstances which grind people down so that their greatly diminished state becomes normalised and aspiration towards self-actualisation is bled away.

8. Appendices:

- Appendix A: Questionnaire text
 - Appendix B: Qualitative Questionnaire responses - Non-financial compensation
 - Appendix C: Qualitative Questionnaire responses - additional respondent comments
 - Appendix D: History of campaigning in Scotland
 - Appendix E: Scottish Infected Blood Support Scheme beneficiary make-up - November 2021
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Appendix A: Questionnaire text

Infected Blood Compensation Consultation

We urgently need your views

The UK Government is undertaking a consultation about the infected blood compensation framework for infected and affected people.

We in Scotland, under the Scottish Infected Blood Forum (sibf.org.uk) and Haemophilia Scotland (haemophilia.scot), are working jointly to consult those who were infected or are affected in Scotland ahead of the UK Government's consultation to take in the views in Scotland and of those infected in Scotland.

The survey should take less than 5 minutes to complete and will remain open until midnight on Sunday 21st November. Please take the time to give your opinions.

If you would prefer to talk with someone over the telephone to complete the questionnaire and explain the questions to you, please call Tommy Leggate on 07513 363 561 between 1pm and 4pm weekdays. You can text your message and details to that telephone number too and e-mail Tommy at mail@sibf.org.uk

We do not require names or any identifiable information, although you are free to provide this at the end of the survey. All personal data is confidential and will not be released in any way outside of SIBF/Haemophilia Scotland.

We have also held two Zoom meetings with a further two being held on Saturday 20th November and we invite those who haven't already attended to come and share and discuss views around this questionnaire and the wider compensation consultation Sir Robert Francis is undertaking.

The next meeting dates and times are as follows:

Tuesday 16th November 11am - 12.30pm

Thursday 18th November 1.30pm - 3.00pm

Saturday 20th November (morning) 11am - 12.30pm

Saturday 20th November (afternoon) 2pm - 3.30pm

Please provide your contact e-mail/details at the end of the survey and we will contact you with the 'Zoom' meeting details.

We will then present our findings to Sir Robert Francis directly.

1. Are you registered with any of the UK Infected Blood support schemes?

- Yes, SIBSS
- Yes, EIBSS
- Yes, WIBSS
- Yes, NIIBPS
- My application is in progress
- Application refused

2. To access any compensation payment, please indicate your willingness to undergo a detailed personal assessment based on what has happened to you, even if you have previously undergone an assessment for any other reason.

- Detailed personal assessments must not be taken.
- I am unsure.
- Detailed assessments must be required.

3. How important is it that you receive compensation payments rapidly?

- Not important at all.
- I am unsure.
- It's absolutely critical.

4. Indicate your degree of willingness for new categories of payment to be established beyond those in the present support schemes.

- I don't want to see new categories at all
- I am unsure.
- It is a must, the existing categories are too limited.

5. Please indicate your willingness for payments to be extended to new categories of people who should be eligible for compensation, for example families and others affected (sons/daughters, mothers/fathers, carers etc.) even if they have not been able to access any financial support schemes previously.

- No, payments should not be extended to these people.
 - Unsure.
 - Yes, payments must be extended to these people too.
-

6. How important to you is the maintaining of monthly payments under the present support schemes?

Not important at all.

Unsure.

It is critical these monthly support payments be maintained.

7. Please indicate your preference for compensation payments to be processed through a UK Government based agency (i.e. from London) or Scottish Government based agency (i.e. from Edinburgh).

UK Government based agency.

Scottish Government based agency.

No preference/don't know.

8. If you are already in receipt of payments from support schemes, would you prefer any compensation to be added on a monthly basis to your existing monthly support payments, or would you prefer a one-off capital sum.

Apportioned monthly and added to the monthly support payments.

Be paid as one-off capital sum.

9. What other services would you regard as compensation other than financial payments e.g. personal care, an apology, memorials etc. {open ended question - text box for response}

10. Would you be willing to take part in a meeting with Sir Robert Francis in person?

Yes

No

11. Regardless of whether you can personally attend or not, do you think Sir Robert Francis must meet in person with the infected and affected community with regard to this compensation scheme consultation, or do you think a zoom or virtual meeting over the internet is sufficient?

- He must offer to meet people face-to-face at selected venues.

- Only on-line/virtual meetings via Zoom or other platforms would be appropriate.

- Physical meetings must take place with Sir Robert explaining issues face to face and being able to take questions from the audience, AND these meetings should be able to

be attended virtually via zoom etc. for those who cannot or are unable to attend personally accepting.

12. Some observers of the process believe there may be a possibility of previous payments received by infected and affected people being considered as compensation, or part-compensation. This might mean they could be treated as 'payments on account' and deducted from any newly designated compensation amount (Sir Robert Francis now calls it "Credit for past payments"). Should any payments you have received already, whether from the support schemes or Skipton/Caxton/MacFarlane for example, be treated as payments 'on account' of compensation or be deducted from any eventual compensation award?

Yes

No

13. If you have any further comments to add, please do so in the comment box below. Thank you.
{open ended question - text box for response}
-

Appendix B: Qualitative Questionnaire responses - Non-financial compensation

[NOTE: Following is the complete qualitative responses obtained from the Consultation questionnaires. It is included as an appendix in line with the determination to ensure that every voice is heard. Except where it is expedient to preserve anonymity, entries are included fully and unedited.]

All doctors, especially those working in Liver units should be made aware of the mistakes made and those in the blood transfusion service should offer an apology to families who continue to grieve for those infected, dismissed by the medical profession and treated so badly till the very end.

Was admitted to hospital for a routine operation as a child, after discharge, experienced severe blood loss, rushed back to hospital and had to have blood transfusion which resulted being given infected blood. I now live with the fact that I have liver damage. The government was responsible, I would like an apology, as I have been affected throughout my life.

I think for them to take responsibility and apologise is critical. Everyone's story is different but at the end of the day this was their responsibility to make sure this did not happen

All above + Palliative Care

just money - deal with rest myself. memorials - don't do any good - ploughed back into cancer or other care

None

Memorial, palliative care cost plus caring cost/time support.

An apology which is very public and high profile for all to see and know what it's all about. Memorials in each country to make them easier to visit. I don't think these need to be flashy or expensive. Contemplative but not extravagant waste of money. Psychological/ mental health care for all who wish it ,which includes affected not just infected, e.g. children, parents, partners. Access to the care system on this basis alone, not in having to have other comorbidity issues or ticking other boxes. Only if these services are needed, not to abuse an already burdened sector. In other words, if they are acknowledged victims who genuinely need care, it should be provided with no further questions asked or hoops to jump through.

Apology and acceptance of government responsibility

I feel especially after the way everything has been covered up, financial payment to the infected & affected would be the minimum compensation. Never going to get an apology are we?!

Apology and memorial

all of the above

I would say someone to speak to such as a psychiatrist

Personal care

An apology from the transfusion services even though the people who took the decisions which led to many deaths are most probably retired now.

Memorial and apology

What other services are available, how would they be administered?

apology

Personal apologies are very much needed. The worry, heartbreak, alienation and suffering we've gone through over the past 37 years at the very least deserve an apology without question.

There must be a full and unreserved apology from the UK government to all parties who have suffered. In addition, those responsible for this disaster should be named and shamed.

This needs to be carefully thought through ?

A formal apology and memorial

Government apology

Apology and a public health campaign that shows both the public and health professionals that people who have had or have HEPC and liver damage are not always drug users or alcohol abusers

A Memorial Plaque at every Haemophilia Unit

A proper apology

personal care - any type of when needed + public apology - meaningful stand up & take responsibility for it - accountability publicly

An account of blame.

Apology...cheaper life insurance...

Extended Personal Care into old age and support for families affected. A full public apology and four capital city based memorials. Immediate access to Counselling for those affected including families.

An apology

Apology, personal care,

A full and public apology as well as a personal written apology and acceptance of negligence.

A free health check annually especially a liver scan

Access to affordable life insurance, guaranteed monthly payments for life for the infected and bereaved partners

A substantial public, sincere apology and ownership fully taken for this disaster

Regular liver scans Regular liver Doctor appointments with scans Life insurance Good standard of Personal care and End of life care

I think that personal care for infected persons and their families may be a practical consideration at present and in the future. I received an apology from the Blood Transfusion Service a week before I gave evidence to the Infected Blood Enquiry. It was poor and the timing says everything about the attitude of the Service towards victims, I had repeatedly commented for years about the Services failure to even contact victims never mind apologise to them.

An apology

An apology with prosecution of individuals subsequently proven to have behaved in a criminally negligent manner.

Apology

Apology

Apology

Memorial, it's too late for apology

Nobody should be worse off as a result of any rebanding,

Personal apology after being infected 45 years ago. Memorial for all those who lost their life also those in future ,that I'm sure it will happen .when????

An apology

Memorial and an apology

Specialist social care (personal, palliative, etc.); a comprehensive apology; memorials in all 4 nations; insurance underwriting by Government; a priority health access card scheme; independent financial and legal advice provision; sustainable funding to go to support groups; compensation and support scheme payments exemption from tax and benefit calculations; benefits passporting; bespoke psycho-social support; carer respite support; provision for aids and adaptations to the home; etc.

An apology to those infected and affected. Greater degree of transparency. Ongoing financial support for those infected and affected. Memorial to those affected.

I think that if financial assistance is made available, then that will go some way to being an apology, more so for people with young families who probably missed out on a great deal.

A simple explanation of what happened in each country and why

The financial payment is sufficient for me.

An apology from those who took the key decisions that resulted in infected blood products being used in the UK.

An explanation of why this happened and why it took so long to come to light.

Admission of guilt which has been proved beyond any reasonable doubt

Care package.

Help with insurance . Psychological support to continue. Apologies

Memorials for ones who have died, yes, no brainer. Don't need personal care personally.

An apology

Palliative Care acknowledgement Better health care

An apology

Apologies

Access to insurance policies, e.g. life insurance.

I think financial compensation is a must, but think apologies are well overdue. Memorials I thought were happening, but definitely should. I don't understand what is meant by personal care. Access to counselling.

Memorial

Psychological services

Free Lawyers

care - don't know as I'm relatively physically healthy, apology - all deserve open - meaningful
Apology most of all

too late for an apology and memorials are pointless

An apology, memorials. Plus lot of support to deal with Hep C for you and family to deal with.

Acknowledgement of the blatant cover up and deletion of hospital files

An apology is a necessity, as long as it is sincere, but also a memorial as has been talked about by the Scottish Haemophilia society

an apology

Personal care and an apology .

It's far to late for an apology and a Memorial is a waste of time

National memorials

Apology

Apology

Memorial

Apology and memorial in each Nation

No other services required at the moment

A BIT LATE FOR THAT

Apology and further education for MHS and Health Care staff, i keep getting asked if i am still on drugs!!

Apology and Memorial

At very least an apology but I believe this would be an empty apology

No, once done its done - get money and put it to bed

apology wouldn't go wrong - when got hcv felt shunned - in 70's

can look after myself, no need for memorial

All above

An apology and accountability

I believe an apology would be required at the very least.

memorials, personal care, legal aid assistant, help with transport, help to share buy car.

Admission of mistakes made longingly, acknowledgement of horrendous impact on people's lives, apology, care for those still living with conditions and memorial to all lost/affected.

a sincere apology and admission from those involved and in power including decision making powers that decisions in the past were made purely on financial basis with no regard to the recipients of the bloods and virus.

Too late for an apology now.

An apology & memorial

Counselling services

don't know, just money

Financial Payment is the most significant, followed by personal care.

I'm really satisfied with the way things are and monthly payments

no, a bit late for apologies

memorial, apology, personal care

I believe there should be a public apology from the UK Government and the head of the NHS. There should also be a memorial created with the names of everyone who was infected along with the names of all those who have died. This tragedy must never be repeated.

Financial payments would be enough

apology - sincerely meant - with ramifications of that ie reparations, and a memorial

apology

First an apology and automatic personal care if required. Should the patient have any personal requests these should also be considered. We aren't all the same.

Not sure

definitely public apology at least

memorial

AN APOLOGY WILL NEVER REPLACE THE DECEIT FROM THE MEDICAL TEAMS, THAT TREATED ME THROUGH OUT YEARS OF LOOKING FOR CLUES N MY OWN.

The decision makers within government to be held to account. People's lives have been devastated by bad choices or cutting corners, governments can't do this in the future or we will see this type of thing happen again

Unsure

No other services that I can think of

An apology would be nice.

A commitment to long term and support to be available when required.

greater recognition of the issue and a commitment to ensure no future repetition

Personal care

An apology

Certainly a full apology and confirmation that the Government was a fault. No wish washy excuses is acceptable. I also think that criminal prosecutions should be made against certain people. They didn't expect us to live long enough to be able to make a case for it. Disgusting!!

Help with mental health/counselling and memorials

Legal charges brought to the people involved. Apologies won't fix my liver, or bring back the dead.

I would like regular check-ups even though I've been treated successfully just to catch the inevitable problems with my liver quickly. Every 2 or 3 years.

Personal care

Permanent recognition of the blood disaster (memorial) in each country of UK; personal care where required

AN APOLOGY OR AN EXPLANATION, WHY DID MY CONTAMINATED BLOOD COME FROM PRISONERS - CRAZY

All of the above

Personal care

An apology

An apology at the very least.

a apology yes but those responsible should end up in court if possible

Apologies, psychologist therapy,

the doctors that infected us should face criminal charges

Access to personal care and support. Access to psychological support for all affected. Grants for private treatments the NHS only deals with the curable many of us have incurable issues arising from the infections and their treatment.

Fund the memorial and have it installed at Holyrood

An Apology, Memorials, also personal care and dignity for all involved.

Family support

Don't know.

Apology

Apology and a memorial

Accountability

At least an apology for ruining my life

An apology! Also help for the psychological effects this has created. 30 years of my life I have spent campaigning, fighting, for my mother. This has cost me my mental health, relationships with partners and split our family apart.

Private healthcare, physiotherapy, counselling and chiropractic services.

An apology

More help for after care since taking the drugs.an apology would me something

Admittance that serious mistakes were made, and that we will now be compensated .

Fast track health care, Direct DWP payments should be a automatic payment with far less intrusive medicals

An apology. An automatic entitlement to welfare benefits without having to go through humiliating assessments carried out by people with little to no experience.

An apology. An explanation for why it was allowed to happen.

An apology would be nice.

All of above

That funeral expenses are taken care of

An apology

Personal care

An apology and memorial

I think that setting up personal care systems such as your recent psychological services are very helpful. I cannot speak for others who have been affected in other and more severe ways.

Support plan for ongoing health monitoring for infected

An Apology

An apology is superfluous. Events and information in the 1970's was scant and no one realised there was a risk. Who is going to apologise for what was done 50 years ago when no one directly involved is likely to be still around. People are receiving compensation. It should be sufficient and adequate for them to be able to live on and they should be able to get at least some priority in care services to support practical needs.

Apology and memorials who have lost their lives to this disease

No apology required

A campaign to help us deal with stigma it would help.

A memorial is a must. One in each devolved nation so that people don't have too far to travel to see one. Also, enhanced medical support (guaranteed liver scans for those infected with HCV even after SVR) must be made available, alongside the proper psychological support for those who require it. Treatment must be easy to access with no hoops to jump through other than being an infected individual, or a previously infected individual who is now SVR. Also, i think having some sort of lifestyle support would help many, like a dietician, physio, etc. There is very little help from hospitals on this regard, people need to be educated on Liver loving foods and diets etc. An apology, whilst meaning nothing to me (too late, not from the people responsible, forced to do it) might mean more to others, and i think it goes without saying that the government needs to apologise for the continued pain and suffering that they have put people through. The UK government, i mean.

Assurance it would never happen again

An apology is essential, for the initial political decisions, and an apology for decades of lack of medical care thereafter.

For one I never received any type of apology after discovering I was infected following several blood transfusions in the late 70's.

All of the above

An apology - 25 years of my life ruined.....

None

Access to a councillor.

An apology and personal care

An insurance scheme to provide insurance for mortgage, travel etc.

An apology

More research into long term effects of hep c

Not sure

An apology

Personal care if needed an apology in person

Apology

Access to whatever healthcare services that are required

A memorial and an apology.

Admit they were in the wrong

Don't know

A sincere apology! Personal care throughout the remainder of our lives especially psychological care

For the government to accept responsibility

An apology should be given but this is not compensation. Personal care should be given on a case by case basis again I would consider this duty of care rather than compensation.

All of the above

Counselling services, Apology

Personal Professional care and support when needed so that the burden is not put back onto the family.

Absolutely essential that the UK government apologise unreservedly for this catastrophe and call to account those responsible.

Palliative care. Insurance and mortgages made easier. Financial advice if necessary. Apologies.

Better healthcare monitoring and quicker follow-up care. An apology.

Palliative Care, apology, specialist Care

An apology, but in addition to additional compensation, not instead of it.

I should never have had the factor 8 in the first place. My blood disorder never to this day been accurately diagnosed. An apology from [redacted] hospital would help. I am now very crippled.

Palliative Care, Passport to specialist care, acknowledgement of wrongdoing. No pip assessments

Yes an apology. Palliative care. Mortgage and insurance made easier. Help for those who need financial guidance.

Continuing psychological support

Apology. Memorial.

A frank and full apology for the wasted lives and the total disregard for the years of misery .

An apology . And continued health monitoring

Personal care,

Memorial

Apologies from staff at RIE especially Professor Ludlum

An apology

Mental health help. personal care. although not a service I would hope everyone is treated fairly with no need to worry about rent/mortgage heating and food.

my lost salary and pension.

My understanding is that compensation is for loss suffered and should be based on a financial payment. It is not legitimate that this pays for a memorial. An apology may be appropriate dependant on who provides it. It may be appropriate to seek compensation to meet future care needs, but this would need to be assessed.

Not sure, depends on personal circumstances at different time.

Appendix C: Qualitative Questionnaire responses - additional respondent comments

The monthly payments have been life transforming for my family and I.

People should get an interim lump-sum payment asap.

SIBSS must be maintained, people's lives and families are disrupted, people have been put through pain for years and live with an uncertain future.

I have answered NO, as I have infected liver and I don't know the long term consequences to my life.

Many thanks for all the continuing work and effort on our behalf's.

About how many people I infected giving blood before they started testing.

Shaking

We have been assessed at the hospital(s), assessed by a former scheme(s), assessed in part to move to the new scheme, assessed for discretionary grants, assessed of employment-related benefits, assessed for disability-related benefits (PIP, etc.), self-assessed for SIBSS using unsuitable criteria, assessed in part to be a core participant in the Inquiry. Oh, and the deeper assessments for various appeals (benefits and schemes). Enough is enough. For the Compensation Framework, if you are registered in a scheme you should be automatically accepted into the Compensation scheme.

The inquiry said that some lawyers/QC's are getting £10,000 per week, paid by the State. Seems like the legal profession is getting more pay outs than the victims.

Whatever they give will never be enough for the lost and dying x

I'm English and was infected in Scotland. I'm grateful to SIBSS and Scots for support I get. Very difficult at start. Anxious to attend meetings face to face. Husband died in 1989, lived in north

east Scotland, now live in north east England. Can't say thank you enough to people in Scotland who've helped us - a life-line - thank you.

I don't know how much I should get in compensation - how much is a life worth?? What value can you put on health? What value can you put on being poisoned, not knowing for 23 years and then being lied to about it for decades?

The new scheme must include provision for people to be supported in accessing the scheme. That includes the two membership organisations being supported into the future ... for people to have access to independent financial advice ... and maybe some will need to have the guidance of a lawyer to get the best settlement for them in their particular situation (especially if we are to avoid long, drawn-out assessments).

I believe people should have the right to go to a tribunal or even seek court damages if they want to. That is why we support lifting the time bar, for example. Benefits of an adversarial process (court/tribunal) are that a person may get more money based on them maybe having, say, lots of lost income if they had to give up a high paying job. They also get "to have their day in court". However, a person could get a lot less money if the opposing lawyers do their job too well, and be further exposed to re-traumatisation, regardless of the outcome. Time delays is also a big factor.

No one apart from the victims of this disaster can fully understand the devastating effect it has on them personally and on their families. It is shameful that the UK Government has avoided accepting blame when other countries, Ireland, Canada, did so years ago and paid appropriate compensation to the victims.

We regarded other countries who are under strict governmental regimes and commit atrocities as cruel and unethical in their treatment of their subjects? I never considered that I would be forced to regard my own country, Great Britain, as anything other than caring responsibly for the health and well-being of its citizens. Trust, security, safety and health and well-being have surely got to be paramount for any caring government. Why then is still waiting for answers? Are we any better than any regimes as described above? I think not. It may be considered by some unethical dehumanised politician to be easier to let them die, easier and cheaper. Are we then to eliminate anybody born with a condition or disability, which is requiring treatment by our health service? As a country, what does this make us? If we wish to be considered to be better than regimes run by despots and tyrants, then we need to make sure that no government or health service has the power to decide to deliver treatments which lead, or almost certainly, will lead to long, slow suffering and death.

This is called torture and murder. Why, then, is there a grandiose belief in those in charge of health? Is it I have the power over you? Or was this a political, governmental view?

Successive governments have made deliberate decisions to 'bury' this atrocity and shown a remarkable disregard for human life. Does a person who is injured??????? in politics render themselves unable to make moral judgements, have ethical standards or are they possibly consumed by self-interest? The fact that this atrocity was buried and hidden for decades speaks volumes about guilt! Otherwise, why hide circumstances? Why not 'spread the word' to save lives, as would have been the case and my husband's situation. How many lives could have been saved with this philosophy? Why the secrecy, deception and lack of truth? This could be described or assumed to be abusive behaviour.

It would seem that governments 'wanted it all to go away'! Wait long enough and they will all die. There are no other reasons I can explain to myself for the neglect and ignorance of acceptable human behaviour as displayed by those ultimately responsible for this disaster.

I wonder how many of these people would feel watching a lovely six foot two young man waste away to a tiny, emaciated small body? This is the reality and result of irresponsible actions - devastating to those who were trying to save his life and those who loved him.

I find it difficult to describe the depth of pain inflicted on me and my daughters at the untimely death of my husband, their father. The initial extreme distress mutates to an unimaginable depth of mental agony as the years have gone by, with no acknowledgement or responsibility taken by those responsible. Tortuous and unending. There is no serenity or peace.

There is also no understanding the depth of depravity which would drive any individual, medical or otherwise, to repeatedly inject someone with a product which was more dangerous than the condition which required it.

I look at the loss of my beloved husband as destroying my life and taking over in my naive belief and faith and humanity. This is not and should not be regarded as a political exercise. It is about human behaviour and suspect casual decision making, which resulted in devastation, destitution, deprivation and further suffering inflicted on those depending on helpful, if not curative, medical care and treatment. You have failed in all areas of care of those requiring blood/bleeding treatments and acted in the most surreptitious manner possible. It would seem that those in charge of decision making require a radical rethink of what is required to deal with complex issues regarding health and welfare.

Does the Hippocratic Oath no longer apply? It cannot be bent/manipulated to suit governments.

Dishonour, dishonesty, disgraceful. Shame on you.

To sum up, the best that I can say is that you have failed drastically and completely and cutting out your duty of care!

The alternative can only be that you deliberately ignored and carried out treatments which you knew could be harmful, destructive or possibly fatal to those who require to help. Unfortunately, honesty is a foreign concept to many people and in possessions.

Governments cannot be allowed to shirk away like thieves in the night? Governments cannot be allowed to 'slide out of this'!

In the event of lack of action, information, financial help for the most affected, one must assume that these reprehensible characteristics were prevalent and persistent.

You had the trust of vulnerable people. This trust was unused and misplaced and must have a consequence for decision makers without protection or Crown immunity.

My answers/comments for Kenneth Clarke: It is quite obvious that you have risen to the level of your incompetence and sunk to the depths of your depravity. You are a fine example of a man's inhumanity to man. Denial of knowledge and ineptitude in the performance of the person in the position of Health Minister is inexcusable. Pomposity as an ineffective cover up and inevitably indicates lack of empathy and humanity. Is the title of Minister of Health merely that? Just a title without responsibility?

How dare you demean the pain and loss suffered by those infected and affected? It seems obvious that you have no human feelings, merely superficial characteristics of humanity. Maybe the ministerial title for you, Mr. Clarke, should have been a Monster for Health!

Nothing really - head's befuddled. Everyone's so different - in their circumstances. I'm older (79 now) and got infection in 1989 and it took 17 years to get diagnosed (2006) I lost my husband a short time ago and I'm lucky to be here & some others haven't been so fortunate. I have autoimmune HCV and the drugs I'm on have many side-effects. I was also put on interferon & ribavirin which was absolutely horrendous - I was bed ridden for 6 months. There's been a cancer link to that treatment regime. I've since had bowel cancer. I know others have had cancers too linked to the interferon/ribavirin.

Regarding assessments, I'm on my 3rd professor now (other 2 have died) and he says if anyone was to assess me they'd think I was alright and I'd get no sympathy!

I look okay on the surface, but underneath I'm a wreck, but I'm also a survivor. I don't think I could handle any form of assessment now - I'm terribly anxious.

I'm living with side effects of meds for autoimmune HCV and have done for the past 15 years. I've got-on because I had no other option. I had to retire as a nurse at 60 as I had no energy and was exhausted all the time. I do understand others who've lost loved ones it must be awfully hard for them & I understand why people get so irate at how they've been treated by the UK Government.

The Scottish scheme must continue and my monthly payments must continue - I depend on them to have any semblance of a normal life (what's left).

Whitehall must not run the compensation scheme, for Scots it must be run from Edinburgh - I trust them more than the folks in distant Whitehall. We got parity payments pretty quick after

it was announced and the Scottish Government were in the middle of an election too and they still managed to get the payments out to people. I heard the poor English folks are still waiting on a lot of parity payments - that's unbelievable that Whitehall would not make it an absolute priority for EIBSS to make the parity payments asap. What happens with Inheritance tax issues? Compensation should not affect income tax or benefit entitlement OR inheritance tax. I feel no matter what, the UK government will take it 'to the line' - I don't think they'll see the urgency in all this - we're all getting older - are they waiting for us all to die off? I don't think it'll be vast sums of compensation, but you never know. Matt Hancock said it was the biggest mistake in all NHS in all its history. Compensation should reflect that.

In response to question 12, I completely understand the logic behind it and with the current global economy being the way it is, even more so. However if this had come to pass in a much timelier manner, when the UK was better off, the issue would be viewed differently. And the tardiness and timing delay is not the blame of the recipients nor for the want of their trying. Secondly, current payments should not be counted morally or legally. People haven't been receiving compensation. That has been made very clear. Aid but not blame related compensation. No blame accepted. If after the Inquiry, blame and responsibility/ failings are reported and compensation is requested by the Inquiry then compensation can be paid. This is what Sir Robert has been asked to prepare for- Inquiry recommendations. A framework ONLY IF it comes to be required. Preparedness. We're not there yet. Even if this comes to pass, how can compensation be deducted from aid paid previously which was clearly stated not compensation. Cart before horse. If current aid is compensation, then "culpability" should have been accepted back then. Shouldn't be allowed to have cake and eat it. Consider this appropriate punishment for all that had gone on before to the victims- denial after denial, deaths without truth being acknowledged, stigmatisation. The list goes on. You can't deduct compensation which was never paid. We merely received financial assistance.

“First, do no harm”

Someone must be held accountable

I prefer monthly payments for compensation - I'm wary of such a large sum of money in my account from a lump sum. I can't attend physical meetings, I'm in Inverness and can't travel long distances so well.

I can only say I feel for the wives and partners that they don't (yet) get compensation with what they had to go through.

I think the process needs to be a uncomplicated and accessible for those affected. Including

those currently living with the disease and widowers and families affected by the impact of their loved one with the disease.

I know we are going through a huge health crisis at the moment, however the people who were infected with blood products should never be forgotten. My father died prematurely due to complete negligence of those responsible for safe blood transfusions in Scotland and the UK. Every family celebration he has missed cuts the family deeply, he was the most wonderful, kind, generous spirited father, anyone could hope for. When I read that smaller countries with much poorer health services and safety structures such as Malta had already stopped transfusion patients with blood from overseas, usually taken from American prisoners, and this country had blatantly continued to use these tainted supplies I was horrified. My father was one of the last people to be transfused with this blood, as late as 1988 in Scotland, there is a long list of countries who had already abandoned using this blood as health concerns had already been raised. Then later when we were still unaware what had happened to my dad following what we thought was major but successful surgery, Doctors were still negligent. Unable to answer his questions of why he continued to have symptoms which no-one seemed to offer any explanation for. My Dad kept diaries as he knew there was something yet unexplained with his continuing deteriorating health, he was never contacted to ask, did you have a transfusion in the 1980's? Surely a simple letter or poster in GP's could have alerted them and us. My father was a fit man in his youth he looked after himself well, played golf, was a hill walker, a strong swimmer. The insistence that all his growing symptoms were alcohol related were immensely hurtful to him and to all the family. Once terminal we were given an answer by an Oncologist who pieced all his history together but by then it was much too late it was not the answer we were hoping for, and within months he was gone. Nursed at home by myself and family, it was an honour to care for him as he had cared for us so very well. No amount of compensation can ever replace him, we would gladly give every penny back if we could have him here with us, I hope Sir Robert Francis thinks of the lives ruined and health affected of other family members through stress and worry. Sir Robert Francis must learn from the mistakes of the mishandled Penrose inquiry in Scotland, with its one recommendation following years of detailed reports. I think he needs to meet with victims and families to show respect for those who lost their lives. All doctors, especially those working in Liver units should be made aware of the mistakes made and those in the blood transfusion service should offer an apology to families who continue to grieve for those infected, dismissed by the medical profession and treated so badly till the very end.

It seems to me unfair and unkind to discuss compensation and then state you have already had some. Previous payments were never discussed as compensation and were awarded, to me, at a time when HCV remained very heavily stigmatised and incredibly frightening which was not acknowledged. Further compensation should include this acknowledgement as well as many other issues.

Compensation should be given asap. This has been going on too long now.

No amount of money can compensate for what we've gone through over the years. My husband died [date extracted] as a direct result of Co-infection. His suffering was unbearable in the end, I nursed him at home for the last 6 months of his life and was his carer for 42 years of our marriage. I was forced to have an abortion in the [year deleted] due to the unknowns of HIV at the time. We have really had a hell of a time and there are no words to describe the fear, the horror, the heartbreak and the secrets we've had to hold to ourselves. A very different life to the one we set out to have when we got married in (the 1970's). Because we live in [deleted] we had to keep everything to ourselves, only a handful of people knew what we were going through. Yes I'll meet with whoever I can to help bring this appalling tragedy to a conclusion for all involved.

It's a disgrace that UK Government might want to treat SIBSS and other scheme payments as any type/form of compensation. The SIBSS payments are support payments and are to be paid to me for the rest of my life and my wife until the rest of her life. To conflate the two is a disgrace and seeks only to minimise the compensation pay out the UK Government will make. I am a haemophiliac, infected some 40 years ago. My younger brother is also infected and he is now very seriously ill and may not survive to see the outcome of the compensation consultation never mind the Inquiry. My Brother, my wife & I have kept the infection a SECRET. My wife has a senior role in the NHS & I feared my infection would impact on her. We also fear our non disclosure of the infection and later revelation of this could impact on her job and prospects and fear that we are seen as 'lying' about it. I haven't told my current or previous employers for fear of stigma-based reactions/limitations. Compensation is LONG OVERDUE. SIBSS payments are helpful. We have paid off our mortgage now which we are so relieved about as I couldn't get life insurance in the past at all to get a mortgage in my name, so our mortgage is in my wife's name. My wife has a good job at NHS, well paid, and I am lucky and grateful for that, and scared at same time that any revelation of my status may impact on her and my job/job prospects. SIBSS monthly payments & Scheme MUST be retained. XOMPENSATION MUST BE IN ADDITION TO ONGOING SIBBS/SCHEME PAYMENTS until I die and my wife dies. Co-infected deserve more than mono infected. Compensation must be "SUBSTANTIAL" COMEPNSATION. It's good that SIBSS offer free psychological supports. Rest of UK should already get this, it's a disgrace they don't. The Scottish Government and SIBSS is not perfect, but I see Scottish Government as taking the lead in the contaminated blood response in the UK. That's why I trust them with Compensation administration.

Nothing should be deducted especially if nothing has been backdated to the date of infection

Absolutely not! Previous payments have never been considered as compensation!

No deductions should be made for payments that have been drip fed over the years!

Previous payments were never classified as compensation so should NOT be deducted from future payments previous payments gave held us all in limbo with constant stress for years

I was infected either in 1969 or 1972 through blood transfusion after giving birth at [redacted] Hospital. Wasn't told I had Hep C until I gave blood in 1995 - 23 years after infection. I had felt unwell for years before 1995 and doctors couldn't figure out why. Was horrendous, it impacted my whole family, my son & daughter had to be tested regularly. Had interferon, took for 6 months and that was horrendous, it wasn't successful and I could only manage 6 months and it had a seriously bad effect on my health - physical and mental/emotionally. I got new treatment 2 years ago and have cleared virus, but damage has been done on so many levels. I am checked up on every 6 months now. I am on SIBSS and getting the severe impact payment. SIBSS is a lifeline to me. The payments must continue and the scheme must continue. Compensation should be paid on top of/in addition to the SIBSS payments. I don't know how much I should get in compensation - how much is a life worth?? What value can you put on health? What value can you put on being poisoned, not knowing for 23 years and then being lied to about it for decades?

People who have been affected should have at least been informed or tested.

It has taken over thirty five/forty years of successive governments/administrations to admit any liability of this catastrophe. Hardship ignored for so many during my adult life, only to think that any consideration of monetary support given so far gives back what was lost in health and opportunity. To even consider that so called 'payments on account' are being considered is to my mind unbelievably cruel. Any scheme payments to date in my case, allowed me for the first time to put my health and family first following decades of emotional stress, hardship and loss of opportunity forced on me by this unmitigated disaster in health care, no more and no less. Anything in terms of compensation going forward would and should be considered the acceptance and acknowledgement of liability and recompense offered for the hurt and loss suffered, by so many (already vulnerable) families and individuals.

I feel the compensation to date although an embarrassment or slap in the face to what happened to people infected with blood products in Scotland and England. This and always has been done cheaply and in my view been a joke. There seems to be a real chance now given the momentum and the hard work of everyone championing to make amends. I feel there is now a real opportunity for the government to acknowledge this and finally let this be settled once and for all with a level of compensation in line with Ireland many years ago which would be substantial in today's money and only fair. The level of heart ache and fight needs to stop so families can move on and this horrible chapter be closed. If this is done along with a proper apology then the community can finally maybe move on with some comfort rather than the scandal continuing to run for how many more years and run more salt in the very still open and sore wounds. I support everything that is going on at the moment which appears to be positive

however am worried that this will not meet expectations of what's fair. I will remain positive and hope finally for a fair settlement and appreciate the hard work trying to get this past the post.

I think that it's really important that parents and children receive compensation in their own right.

In an ideal world detailed assessments would probably be appropriate but there is no time, this whole thing has dragged on for decades already and hundreds of people have already died without receiving any compensation or apology. For the same reason, I feel the possibility of adding new categories would delay the process as well. We must remember that the people involved would like to have some kind of quality of life and closure for whatever amount of years they have left in front of them and this is where a lump sum would be beneficial, to achieve goals so far impossible, i.e. moving house, holidays, financial stability most of all. Only in the past few years infected people have managed to obtain mortgages, thanks to the ongoing payments, and a lump sum would help to clear these. Personally, I maintain that there is no right value to someone's life, so we could discuss this until we are all dead. Therefore at present the priority should be achieving something quickly for the infected. In the event that they are already dead, next of kin should be treated with the same priority. Any other connection should be secondary. I will happily give up my compensation to ensure my husband gets closure quickly, this has affected his whole life and he deserves to now settle and have some kind of peaceful years ahead.

If there is only a small amount of money available for compensation then carers not registered living in the household should not receive any compensation. Compensation amount must be what our monthly SIBSS amount is, backdated to date of infection and also keeping our monthly SIBSS money for life. The SIBSS monthly amount and compensation must not be means tested. There must be an extra tariff for Haemophiliacs as our bodies have been repeatedly infected over and over again and have been used as guinea pigs by the doctors which has been proven at the Inquiry. There should also be the option for people who do not want a lump sum compensation amount to add it to their monthly SIBSS amount. Whatever happens we must not be financially worse off.

I am uneasy about the questions asked here. Means testing, Credit of accounts from previous support payments? Nothing about any action against the people knowingly responsible for this disaster. I would ask that the Chair look at some of the disgusting holier than thou testimony given to the enquiry by the leading politicians of the day. Surely when compensation is being discussed the knowingly harmful or downright incompetent decisions of such people should be part of that process. These people had been told of the problem and given solutions which that completely ignored. I listened to testimony that intimated that action had been recommended prior to him coming into post as Health Secretary and had not been done. It then appears to have been "too difficult" for him to get off of his condescending backside and

do something. I just wish that the victims could question these incompetent narcissists. I for one would not miss them.

Payments were no compensation and should not be considered compensation! Not one person should be worse-off as a result of any changes!

Previous payments were NOT compensation!!!

Absolutely not it wasn't compensation! (regarding previous ex-gratia and scheme payments)

Previous payments should not be considered as it was not compensation!

A suitable memorial an apology and no individual assessments as people have been through enough, lost jobs, businesses, family members lost all dignity so no more, individual assessments

I find question 12 very annoying even to suggest, if it wasn't anyone's fault but we all know the truth!!!!!!!

I am concerned about the very short timescale for people to participate in the Compensation Framework Study. I am concerned about only having virtual meetings with people in groups rather than facilitating a means for people from different groups and areas to discuss options rather than be stuck with holding on to potentially outdated or ill-informed positions which did make sense at the time of first consideration, but which may now be unhelpful. I am concerned that there is the potential for this process to result in victim cohorts being placed in competition with each other, as a form of divide and conquer. I am concerned about the Study having a remit limited to what should be compensated and who should be compensated, but leaving the amounts of that compensation package to be set by Government. I am concerned that there may already be an immovable set budget for Infected Blood compensation and any enlarging of the scope of what counts as harms caused, or the range of eligible people, will compromise the achievement of fully substantial compensation payments, since that will naturally arise from the sense of having to spread the suspected total amount ever more thinly. It should be a bottom-up process which firstly determines the compensatory value of the harms caused by the State, then afterwards does the calculations to arrive at a total to be paid out; and then the State has to find the money required. A debt is a debt and the Government cannot shirk its responsibility to support those it harmed by making a lame counter-claim to protecting the public purse. This is not a blank cheque concept, since it should be possible to arrive at a total amount which will be reasonably accurate. Having a top-down approach which forces a limiting of payments due to a figure on a spreadsheet would

defeat the ends of justice being sought through the Inquiry and cause yet more harm to those who are already irreparably damaged by the Contaminated Blood Scandal - the worst treatment disaster in the history of the NHS.

People should not be made to feel like that they are not due compensation if they have been able to work and earn a good salary. The impact that receiving contaminated blood may have had an impact that can't be determined or understood.

Any revised compensation scheme should account for the psychological impacts of the consequences of receiving infected blood products & not just the physical impacts.

Being given infected blood has impacted greatly on a lot of people's lives, including my own, and so it is important that we are compensated for this. Other countries have paid compensation so I don't see why we are so far behind.

Hep C ruined my life. Had childhood leukaemia and got Hep C from blood/plasma for that, at [redacted] hospital, then [redacted]. Had leukaemia in bone marrow. Got treated from 1986 to 1988, Born in 1971, my birthday is [redacted], [redacted]. Don't know how I'm alive still. Now scared of socialising, going out. Have arthritis, sciatica, back problems, can't go for walks in country like I used to. Getting severely impacted payments from SIBSS. They are a Lifeline. Had two bad experiences before with one psychiatrists saying I'm making it all up. Had traumatic experience at [redacted] Hospital. I self-harmed as child and into my early 20's. Can't walk much, get taxis to where I need to go. Dad helps a lot, he's 72 and drives me about places. He has his own health problems. Hep C took it out of mum & dad too, they've been through the mill with me. I have bad memory problems. Benefits/Job people think I'm 'at it' and don't believe me. SIBSS payment is a lifeline. Hep C ruined my life and mum & dad's lives, was bad enough beating leukaemia but Hep C is worse. It's changed my 'head' over the years. I've not had a relationship with a woman for over 15 years - can't bring myself to tell women/people about Hep C. (Note respondent broke down half way through the telephone survey)

The reason I don't think any past payments should be deducted is because in the government own words these were not compensation payments and it is high time they stood up and show why we are called Great Britain and do the right thing by those infected not try and cover anything else up or penny pinch

Got hep c from plasma at childbirth from {blank} Maternity Hospital - lost my baby. This was in 1986 & I didn't find out I got Hep C until 19 years later! I went to my arthritis clinic and they found out from blood tests there/then. It's impacted on my work & home life, I am drained, have low energy. I got interferon and my hair fell out and I was bedridden for 6 months. I

suffer from depression, had years and years of a bleak black outlook, really bleak times. Always expecting the worst to happen as bad things have happened to me through no fault of my own. There should be no clinical assessments - we've already been through all these, repeatedly. Lump sum needed - we've waited long enough. They've dragged their heels for long enough. Get this over and done with quickly. Especially for bereaved families who've been through the mill and those who got transfusions and can't prove it - so they can't get on any scheme - outrageous scandal, utterly disgusting!

No personal assessments - records stand for themselves, already done repeatedly. Assessments would just prolong things even more. Rapid compensation - critical - old & unhealthy people need it now, so yes critical. Mother excluded re category - worry, crying for son Support schemes payments for day to day costs for now & future, compensation for date of infection onwards and into future. Would be great if Sir RF went to one of SIBF's weekly zoom meetings on Thursdays evening! High time somebody took the blame & admitted it was their fault. Instead of Kenneth Clarkism, arguing, fobbing off. Already had David Cameron et al; saying sorry. How many times do they say sorry until get it sorted. If they can do it for Grenfell/Windrush they can do it for us. They can let convicted bombers out of jail & pay them compensation, yet we're still left waiting for decades for compensation & justice! So in short, stop the f'ing about and get it sorted!

Any time I have contacted the Scottish infected blood and The liver Trust they have been enormously helpful to me. However I now live in New Zealand where the medical care is very stretched and not nearly so good as the UK used to be. They don't have the same financial input and medical staff are very overworked so the long term care and support for a person like me living with a post Hepatitis C body and liver cirrhosis is negligible unless I can pay privately.

It is very difficult to explain in full detail what it has meant to be infected and how this has affected one's life.

I don't think the non-haemophiliac infected / affected people get enough air time and seem to be side lined by the haemophiliacs by and large. Feel like poor relatives, even though many of them are still here to tell the tale my Dad died July 1984.

Previous payments should not be considered as it was not considered as compensation!

Impacted whole family, 5 kids + 2 girls, relationship should've been more loving, lack of trust, fear factor + work but at bottom of ladder and no promotion - could've bettered myself and

provided for my family. SIBSS payments have been an amazing lifeline. Phoned SIBSS up to thank them and was crying on phone, woman at other end was crying with me.

The Inquiry is proceeding more slowly because of Covid which means that any compensation will be delayed. If The Inquiry will report much later because of Covid. An interim report (if culpability is found) would hasten the compensation process. We are all getting older and many have life-shortening health issues. We all seek closure.

Lots of parents have sacrificed their entire lives and careers looking after wanrable (vulnerable) disabled children with infected blood I believe they should be compensated as well

Sounds like the future of the payments is uncertain which is a concern and has worried me in the past. It also sounds like there may well be some rowing back in the amounts awarded. I am of course, referring to "credit for past payments" paragraph above.

My father contracted leukaemia when he was 32, and received many plasma and blood transfusions. One was tainted and he was infected with Hepatitis C. This affected his whole life. He survived the leukaemia and lived for another 30 years, but always lived in shame as he was ashamed of having hepatitis c. It affected his health in so many ways and he had to make so many adjustments, which affected our family life and the things he was able to do. He was always so scared of giving it to my mum or I, and was so ashamed of his condition as he thought people would think he was a drug user, so he would never let people know of his condition. His liver was badly affected, and that meant is quality of life was substantially reduced, and therefore quality family time was hard sometimes. He died in 2016, after having treatment to try and cure the Hep C, which actually affected his lungs adversely and he unfortunately never recovered. My children were small and they now are missing out on the opportunity of growing up knowing their grandfather.

Haemophiliacs should be treated as a separate group from the other victims. We were repeatedly infected and those in charge knew it was happening....but did little to stop it. The SIBSS payments, and those in the other home nations, should continue for life (as happens in Scotland) but should have no bearing whatsoever in the compensation amount awarded to recipients. Victims should receive compensation as soon as possible given the rate haemophiliacs are dying. A substantial 7-figure sum should be paid directly to them in the form of set compensation without assessments/reviews etc. if someone is already receiving SIBSS (or other IBSS payments) this should be sufficient evidence for compensation to be awarded asap.

Compensation should be paid to deceased estates

Previous payments were not ever compensation and should not be considered!

Previous payments should not be considered as it was not compensation!

MILLIONS SPENT ON ENQUIRIES WHEN WE ALL KNEW THE WHAT HAPPENED

Previous payments should not be considered we have been through enough, we need a quick conclusion with compensation and apology

40 yrs compensation - what is it for 40 years of my life How can you estimate it they've destroyed my life, can't put number on a life

No, happy way things going. Quite happy with what I'm getting from SIBSS/Scot Gov

Wife has cancer - from hep c - liver impacted now tummy cancer. No way should support payments be stopped or counted as poa for compensation. People are entitled, they shouldn't have to ask or be assessed yet again! We're all elderly, we're both 84 and can't attend physical meetings with Sir R Francis.

I have said that meetings with Sir Robert should be face to face but also said I would be unable to do this myself. This is because of how this has affected me and am sorry I don't have the courage to do this myself but hope other who can will be able to do this .

If still around the members of the government at that time of the cover up should be personally held accountable

I do not believe anything will come out of this as it has dragged on for too long and no one could understand the effects on people and their families lives. There are people still alive today who were involved in the decisions but who still contend and deny involvement and treat us with extreme disrespect e.g. Kenneth Clark

Existing payment MUST be increased every year by at least 5% above the rate of inflation.

SIBSS very well, grateful. Doesn't bring her back though. Helps a lot financially though. Thank you. Don't want to meet face to face as am 84 and can't get about too well.

The compensation I think is fair

Many people infected and affected have campaigned for close to 40 years seeking answers, an apology and recognition of what has happened to them. Sadly many people are no longer around to see their campaigning reach these final stages. And final stages it should be. The UK Government have a duty of care to the survivors and the families of those who have died. 40 years of mental anguish and detriment. Declining health, losing friends and family long before their time. The impact of this tragedy on 1000's of people who simply attended hospital seeking help and were left broken. Mentally broken. Financially broken. No amount of money will ever make that pain go away but whatever the final compensation model is, it must make amends for the horrendous treatment of the victims by politicians and clinicians who up until now haven't shown any genuine remorse or acceptance that things did go wrong that could have been prevented.

Compensation should be paid to those infected, and to the estates of those who have died. Then the compensation payment can be apportioned among those less directly affected by the victims. There cannot be an unlimited pot of money, so it needs to compensate those infected.

I get anxious at face to face meetings - if I could meet him face to face, I would, but what's happened to me has left me emotionally crippled with anxiety. There should have been MUCH more notice for meetings - the meeting for widows was too short notice, I know 2 who wanted to go but couldn't due to short notice and 1 who applied for an invite and never heard anything back - maybe that's because she applied on the morning of the meeting - again too short notice all around. How can you get a meaningful consultation if your arrangements to consult are like this?!

Carry on as is with monthly payments .Through no fault of my own I am unable to work and this helps my family immensely.

Past compensation payments should not be taken into account when considering future payments.

in my opinion it is vital that the wide scale differences between those affected seriously, those affected in a minimal way and everybody in between is recognised rather than an overly simple mechanism and that this is reviewed semi regularly as it is clear that with the current 3 scale compensation is not wide enough

Compensation must be on an individual basis. I had to retire at 51 due to ill health as a result of my infection. I had an excellent job with an excellent salary (c. £75k per annum plus car, private health car, etc.). Now I'm not saying I would have worked to 67 but that option was taking away from me. If it wasn't for the monthly SIBSS payments I would not be able to live at a good standard of living. I have applied for a number of benefits and been declined each time.

Payments already received, do not even come close to most of the compensation given by other countries with similar issues. As a haemophiliac, we were the "patient zeros" if you will, what was done to us cannot be undone. Anything less than what was awarded in the Irish settlement of tainted blood, would be completely unacceptable.

Sir Robert Francis' infected blood compensation framework should not be used by government as a means to 'water down' anything that has previously been awarded to those infected or affected by the disaster.

I WAS INFECTED IN 1983 AND ONLY RECALLED IN 2016, WHY DID THE NHS NOT RECAL ME BEFORE THEN, I HAD TO HAVE AN OPERATION ON MY STOMACH IN 1984 AS I WAS CRONICALLY SICK AFTER MY 1983 BLOOD TRANSFUSION and suffered for 35 years

I believe there should be a seriously substantial lump sum paid which reflects the huge hardships, loss of life quality and emotional turmoil of all infected and affected, as well as ongoing monthly payments of at least £30,000 for life.

Living with a potentially fatal virus day in day out has a devastating effect on a person's life. Frustration that I was knowingly given a deadly virus by health professionals in whom you put faith and trust is horrific, a death sentence imposed upon innocent people and the effect on their families should at the very least be heavily compensated. The whole suggestion that any previous payments be deducted is quite sickening.

The question of why paperwork (our records) where destroyed and who ordered it .

They must not deduct payments and payments need to be payed now

Totally against personal assessments as I've been assessed often enough regarding my health problems with Hepatitis-C. It affects my Mental Health these assessments make me feel as if it's my fault it's only recently that we are treated with a bit more Respect from the DWP assessments. These assessments of Victims Of The Contaminated Blood should be stopped immediately. As they are affecting my health.

Question 8. I feel it is more appropriate for me an HCV and hep a infections sufferer to receive regular payments. How people with a co-infection with HIV don't have the same life expectancy and can't get mortgages regular payments don't mean so much to them as they might be dead in the next ten years. I think co infected should get a lump sum. I have really struggled financially my entire adult life until I got regular payments from SIBSS. I would be lost without them with no easy way to explain to benefits people why I have extra money.

Its time all Infected and Affected people were treated with the dignity they deserve.

Thanks for all the hard work that SIBSS are doing

This has been going on for 40 plus years, cost millions on various enquires, no one has been held accountable for this and the appropriate compensation has still not been awarded to those individuals and their families affected by this appalling travesty that has touched so many lives over the years.

I think to take back any payments already made is an insult to all those affected I've never been able to get a mortgage and am still paying rent at 61 years of age and have nothing to leave my children

I just want this to end. I want to be able to get on with my life and start rebuilding it.

Lives are on hold due to the ongoing damage to all those affected. It is important that compensation be provided as soon as possible to allow people to utilise sums immediately. Further the monthly scheme should continue indefinitely as people's circumstances are varied and many are reliant on the payments to stay afloat in the quest of a somewhat "normal" life. Further, family members including spouses should be provided for as they bear the brunt of

caring and supporting those affected by infected blood. Recognition and payment should extend to them too for the vital and invaluable support they provide.

The reason I stated I wouldn't meet face to face is a very personal reason. I think he and his team are doing a great job.

We have went through decades of absolutely no money it's only now we are starting to get what we should, no past payments should be considered

Please don't let us down. I was 23 years old when I was infected with contaminated blood. In those 40 years my health plummeted. I lost my own youth. My children's youth. My marriage. My career. Alongside I had to endure stigma. Ignorance. Discrimination.

I am not very good at speaking and talking about my situation in public I get very anxious even filling in survey has made me anxious as not sure I've ticked correct boxes

I am 72. Monthly payments are helping my family. A lump sum would allow me to do something more significant to help my daughter and son progress in life. My hepatitis C prevented me from participating more in their education. I want to provide some compensation for them

Compensation needs to recognise that for those infected as babies, that this effectively killed any chance of getting a career. If claims are to be based on provable loss of earnings, then a provision needs to be put in place for those whose careers were cut short from the very beginning, and those people should be paid a premium for the loss of opportunity. If compensation were to only be paid on a losses basis, then those who were well enough to work and receive a nice wage for years, will end up receiving more money than those who have lived their lives on the poverty line, unable to work because of the infections they were given. *Those infected as babies or children must be recognised as a special category*, it must be recognised that these people's lives were taken from them before they were able to even begin. Many people, like myself, were only told of our infection as teenagers, were also told our life expectancy wasn't great. As a teenager, being told you are going to die is not a motivator to start planning your career, It effectively derails us from the start, and this must be recognised in my opinion. I personally tried multiple times to pursue university / college courses to learn my desired profession (computer science) but the infection symptoms caused me to drop out every time. Even after that, i tried becoming self-employed as a web designer, which I had to stop doing because the brain fog was affecting my ability to code websites. All of this was because I was infected as a baby, so by the time I hit my teenage years into adulthood, the symptoms were at their worst, stopping any career dead in its tracks. This type of case must be recognised in any compensation scheme.

It is important to fully understand the impact HepC possibly has had/is having on people's life's span

Was put under the table for too long and stigma sticks and everyone is left to deal with this every living day of their life and must continue on in family's life after losing someone

Unless you have lived with the true impact of what this means to a family you will never understand. No amount of money can compensate for the overall impact and effect it has short and long term

NHS must pay out

We have all been infected/affected by this in different ways and levels, but nonetheless have been infected. If compensation were to be paid, i personally would hope that it would be a simple process and not have to drag up again any medical records and have to go through all that again! I also personally would hope that if they did decide to offer compensation, that the option to keep our monthly payments as an alternative to a one off lump sum compensation, would be available as an option to choose for us.

On the last question, payments to date have been ex-gratia without acceptance of liability; they have been voluntary. It is not appropriate that these compensation payments should be deducted from any payments under the Sir Robert scheme. We need to encourage responses to the current consultation by individuals but many will need guidance on the strategy to be adopted in responding e.g. we need to give a consistent message for the community.

I believe that each person should get the same amount of compensation regardless . It should not be calculated on loss of earnings etc.

I think that it is important that compensation given for those who were infected but have not suffered long term effects. The compensation should be to recognise that wrongdoing was done and that the potential for serious and terminal health effects were passed on indiscriminately and therefore everyone who had been infected has suffered. There should be a separate fund to ensure those with long lasting health problems and loss of income are appropriately taken care of.

The impact of me contracting Hep C via infected blood and passing on to my family has sadly been huge with ongoing negative consequences.

This process must be consolidated soon.

Compensation must be paid in line with the sums awarded in Ireland and Canada

I have answered questions in relation to my son's circumstances.

Nobody must be left worse-off and nobody should be forgotten.

No tax should be taken. Benefits should not be affected

You can't tax or take any payments from us as they were paid out as ex- gratia money to help our living standard for life. The Government have not paid out any compensation or took responsibility for their actions and why are you going to tax or take money of infected and affected when it was the government that infected us in the first place.

Clarity should be given re backdating e.g. father is 94 and might not live to see conclusions

Well done!

I don't know how the scheme will be seen, my income loss in in 7 figures. Is mine any more important. I periodontal feel we need to see a scheme which recognises, the actual loses of its members. I am happy to part of a general scheme as long as the amount is generous and reflects both financial, physical, mental losses. If this isn't possible I would like for cases to be heard on an individual case. However as said if the amount is sufficient to make up a higher percentage of losses, in this instance I would be content

If the previous ex Gratia payments were said and named as compensation then deductions could be argued but as it was ex Gratia I can't see how this could even be lawful. Pathetic idea from people who you would think clever and helping.

Appendix D: History of campaigning in Scotland

While campaigners in Scotland have been active since the earliest days of the infections the majority of the specifically Scottish elements to the campaign date from the establishment of the Scottish Parliament in 1999.

1999 - Affected people submit petitions to the Scottish Parliament Petitions Committee, two of the first petitions to be considered under the proceedings of the new Parliament.

2000 - The Scottish Executive publish an internal report but the Scottish Parliament Health Committee concludes it needs more and conducts its own inquiry.

2001 - The Scottish Parliament Health Committee publishes a report recommending that an Expert Group is established to look at the issue.

2002 - An Expert Group is established under Lord Ross and calls for financial support payments to be made.

2004 - The Skipton Fund is established across the UK and makes ex-gratia payments to those infected with Hepatitis C.

2005 - The Scottish Parliament votes 56 to 52 against establishing a Public Inquiry.

2006 - The Scottish Parliament Health Committee calls on the Scottish Executive to hold a Public Inquiry but the call is rejected. Thompsons Solicitors works with affected people in Scotland to bring a Judicial Review of the decision not to hold a Public Inquiry. The Department of Health (UK) publish an internal report on Self-Sufficiency in Blood Products in England and Wales.

2007 - The SNP manifesto contains a pledge to hold a Public Inquiry. At the same time a UK-wide Independent Public Inquiry under The RT Hon the Lord Archer of Sandwell QC is established and based in London.

2008 - The Scottish Government loses the Judicial Review and must now investigate all deaths caused by contaminated blood or blood products. The Scottish Government announce that a Statutory Public Inquiry will be held and the UK Government declines to convert it into a UK-wide Statutory Public Inquiry.

2008 - Lady Cosgrove was initially appointed to be Chair of the Public Inquiry but she couldn't carry out the engagement and an alternative had to be sought.

2009 - Lord Penrose is appointed to conduct the Scottish Public Inquiry and holds a preliminary hearing. Affected people are invited to make written statements. The Archer Inquiry publishes its final report.

2010 - The Penrose Inquiry publishes a Preliminary Report of established facts and details topics it will be investigating. Of the over 80 affected individuals who applied to be Core Participants just 20 affected individuals are accepted.

2011 - The Department of Health (UK) publish their 'Review of the support available to individuals infected with hepatitis C and/or HIV by NHS-supplied blood transfusions or blood products and their dependants' in England and Wales.

2011 - Following the publication of the Archer Report improvements are announced to the ex-gratia support payments available in England. The Scottish Government announces it will broadly match the changes and will review them again once the Penrose Inquiry reports.

2012 - The last public hearing of the Penrose Inquiry is held and statements from the Chair indicate a report can be expected within 18 months.

2013 - The Scottish Government announces it has asked the recently established Scottish Infected Blood Forum to conduct a Scoping Exercise into the impact of the infections to inform its review once the Penrose Report is published.

2014 - Haemophilia Scotland published a report on outstanding recommendations from the Lord Ross Expert Panel Report 10 years earlier.

2014 - Factor 9 was a powerful play, written and performed by Dogstar Theatre Company, attracts large audiences and wide acclaim during the Edinburgh International Arts Festival.

2015 - The Scottish Infected Blood Forum publish its Scoping Study Final Report in March 2015, before Penrose reports. It makes 16 recommendations.

2015 - The Final Report of the Penrose Inquiry is published. Campaigners are disappointed that there is little analysis of the events it describes and only one recommendation; that the Scottish Government takes all reasonable steps to offer a Hepatitis C test to everyone in Scotland who had a blood transfusion before September 1991 and who has not been tested for Hepatitis C. The Scottish Government issues an official apology and accepts it has a moral responsibility to those affected. Apologies are also made by the Scottish National Blood Transfusion Service (SNBTS) and the UK Government. The Scottish Government establishes the Scottish Contaminated Blood Financial Review Group to review the ex-gratia support payments and later accepts its recommendations. Representatives from Haemophilia Scotland and the Scottish Infected Blood Forum are appointed to the Group.

2016 - The Penrose Inquiry Short Life Working Group is convened to advise the Scottish Government on the most appropriate way to implement the Penrose recommendation. It recommends that an awareness campaign be conducted within the NHS and that detailed work is conducted to follow up on a previous look back for people with inherited bleeding disorders. Its recommendations are accepted by the Scottish Government.

2016 - A Memorial Service for those who died as a consequence of their infections hosted by Haemophilia Scotland is led by Richard Holloway, former Bishop of Edinburgh and attended by The First Minister, Deputy First Minister and Cabinet Secretary for Health.

2016 - The SIBSS is established offering enhanced payments to those infected in Scotland compared to payments made previously via the Alliance House Organisations.

2016 - Virtually all infected people with bleeding disorders have been offered the new Direct Acting Antiviral (DAA) treatments for Hepatitis C with the vast majority achieving a sustained

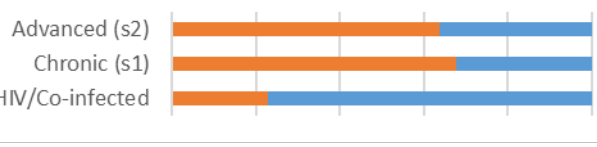
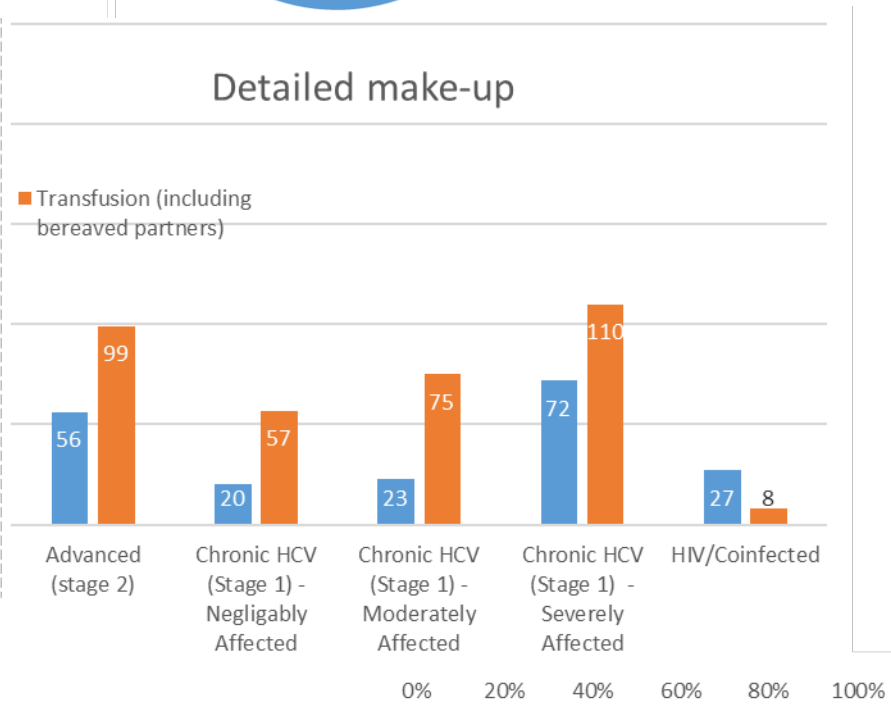
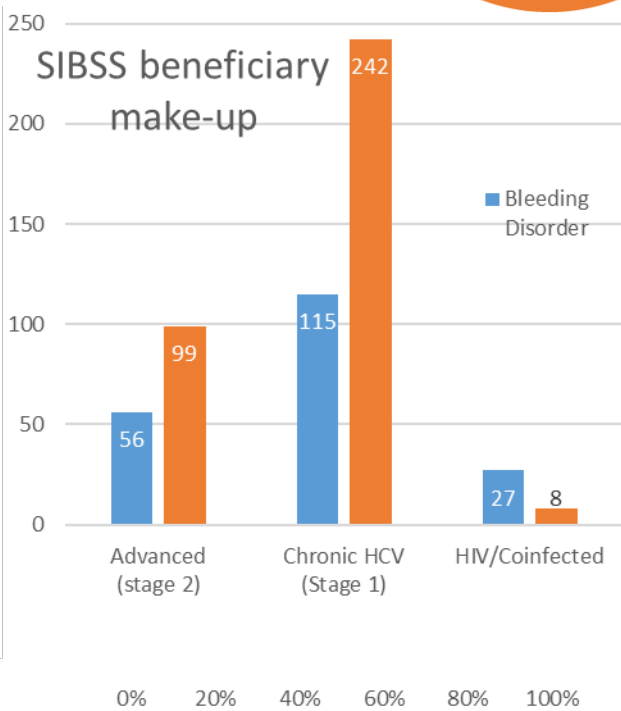
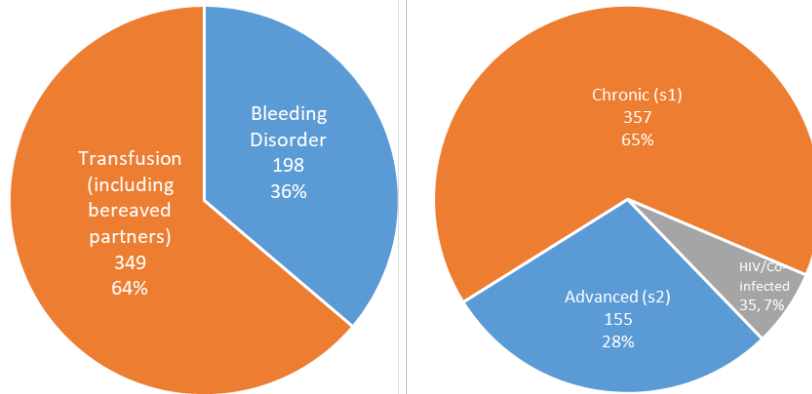
virological response (SVR). Patients now expect to live longer and healthier lives. Access to DAA has not been as good in the rest of the UK.

2017 - The Scottish Government announce that the Clinical Review Group arising from the SCBFSG Report will be chaired by Prof David Goldberg. Representatives from the Scottish Infected Blood Forum and Haemophilia Scotland form part of the Group.

2017 - Following receipt of a cross party letter supporting a UK wide Inquiry the UK Government announces a Public Inquiry.

2018 - The Clinical Review Group completes their study and Scottish Government publish the report. Scottish Government accepts all the conclusions and recommendations. An innovative and unique 'self-declaration' system for chronically impacted people is established within SIBSS.

Appendix E: Scottish Infected Blood Support Scheme (SIBSS) beneficiary make-up - November 2021



Chronic HCV Self Assessed

