

Finding a fair and just compensation scheme

**The Haemophilia Society's submission to the
Infected Blood Compensation Framework Study,
December 2021**

Executive Summary

The process of trying to place a monetary value on the life of a beloved parent, sibling, spouse, partner or child is something no one should be faced with. Nor the torment of reflecting on the unknowable - the 'what might have been' if chronic ill-health, loss and stigma had not permanently altered life's path.

Compensation has long been a major goal of all those who have suffered because of contaminated blood and blood products, yet the reality is complex, with the potential to worsen existing trauma if handled badly. We ask that the compensation process is underpinned by compassion, and that each claimant is treated respectfully with the understanding that they have suffered irreparable damage as a result of this scandal.

For many, compensation is about far more than money. Meaningful compensation must include explicit recognition of the pain and suffering each individual has experienced.

We cannot continue without paying tribute to all the dedicated campaigners who have fought for compensation over the last three decades, many of whom have died as a result of their infections before any government was prepared to face up to its responsibilities.

Our thanks go to everyone who has taken the time to share their thoughts with us on this most difficult and emotive issue. We have worked hard to reflect those conversations, coupled with the results of our own survey on this issue, in this submission.

We would like to thank Sir Robert Francis QC and his team for the opportunity to contribute to the Compensation Framework Study.

In summary, we call for the following:

- anyone who has been significantly affected by the contaminated blood scandal has the right to make a claim
- continue existing support schemes alongside any compensation scheme
- compensation must be sufficiently personalised to ensure that it reflects the loss and damage suffered by an individual, but the framework should include set tariffs to allow a faster yet robust system
- fast-track an emergency payment for those in urgent need to alleviate their suffering
- an up-front lump sum to be paid to the infected and affected community in advance of the full amount
- a clear, straightforward process which is easy to use
- specialist support for people making applications, particularly where evidence has been lost or destroyed. These claims should be approved on the balance of probabilities
- total parity across the devolved nations
- any compensation package to be funded by the Westminster government in recognition that this scandal happened before devolution
- a system which allows transfer of information from support administrators to compensation schemes to reduce burden on claimants to provide information
- a transparent appeals system
- previous payments should not be taken into consideration
- inclusion of non-financial elements in the compensation package, such as psychological support, health passporting and government-underwritten life insurance

- free independent financial advice to be available to all receiving compensation
- any individual assessment to be made by a judge-led panel but must include representation from the infected/affected community
- widen eligibility to include impact from viruses or exposure to viruses currently outside support schemes, such as hepatitis B, and the impact of vCJD.

Introduction and Background

The Haemophilia Society has represented people living with inherited bleeding disorders across the UK for over 70 years and has multi-generational relationships with many families, a significant proportion of whom have been affected by the impact of infected blood products. A large part of the community has suffered the stigma of living with the viruses and want to remain anonymous, but still have a desire and right to have their voices heard. Therefore, we decided to send out a survey that could be filled out anonymously.

This was distributed as a hard copy and emailed to all members with an interest in the inquiry and was freely available online and through social media. Those responding are not exclusively from the infected, haemophilia community, but also include the affected and people infected through blood transfusion.

We based the questions on some of the key themes that emerged from virtual meetings about the compensation review and from speaking to individuals and campaign groups. Due to the complex nature of this issue, we felt it was useful to ask discrete and, in some places, presumptive questions to give a framework to aid peoples' thinking. We did have the option for free text, with no word limit, so individuals were free to express their opinions fully.

We received a total of 405 replies, and the full breakdown of the results can be found in the appendix.

We held 3 virtual meetings about compensation to assess our members' views. The first was about the compensation review's terms of reference and attracted about 30 people, the second, which about 35 people joined, included a presentation from Brian O'Mahoney, Chief Executive of the Irish Haemophilia Society about the compensation system in the Republic of Ireland. The last meeting was attended by about 45 people and discussed the results of our survey.

We have used the answers to the survey, as well as thoughts and opinions gained through conversations with our members individually and through online meetings, to inform the content of this submission. We recognise there are a range of views on many issues and that all individuals and other groups have a right to submit their own opinions. We look to make a submission on behalf of those who have interacted with us.

Support schemes and long-term payments

On the question of ongoing support payments alongside compensation payments, there was a large majority who wanted these to continue (81%). Many people who are already beneficiaries are keen to have the support schemes continued as they see them as separate from compensation: All text in italics are direct quotes from respondents.

Yes, support schemes are not 'compensation'. They should not be conflated together. Compensation should be completely separate and be from point of infection(s) and compensate for past, current and future impacts.

There were comments from those who have never been part of a support scheme that they would prefer a lump sum payment as they were a parent or child of a lost loved one, with acknowledgement that those living with infections may want regular payments to continue.

There was also a recognition that people at different stages of life may have different needs and there were many comments suggesting that there should be options available to suit individual circumstances.

Younger people would benefit from an ongoing payment but older people (or relatives of people who have suffered but are already deceased) may prefer a single lump sum. I therefore feel it should be based on individual circumstances.

One area that did provide a consensus was that ongoing support should be on a statutory footing and guaranteed for life, with 96% answering yes to this question.

The existing ex gratia schemes must be maintained and protected. They should be guaranteed for life, and this should be secured by primary legislation.

People deserve security and to be able to plan their futures with certainty.

When it came to the question of whether the support payments should continue to be administered through the current organisations there was a mixed response, 41% preferring the current administrators, 18% wanting it to be via a compensation scheme whilst 35% not expressing a preference.

Based on the interactions over the years with members there are many who agreed with the quote below,

Better the devil you know.

This is a phrase we have heard numerous times, with members fearful of being taken back to square one by new administrators. They do not necessarily endorse the current schemes, but rather do not want to risk getting something worse. There were comments suggesting differences between the devolved nations systems some being easier to navigate or more efficient than others.

Many people who replied have not previously been involved with the schemes due to being ineligible under current criteria so were not able to comment on this. There were a few comments wanting any scheme to be separate from government.

Should be independent from government and guaranteed.

Another comment perhaps reflects some experiences of the past and not wanting to feel, as many have, that they are going “cap in hand” to either a charity or government department for money that they consider is rightfully theirs.

Some system that doesn't feel like a government benefit that you have to apply for!

The final comment seems to best summarise what people want:

Something that works. An organisation that respects us and just ensures payments are made with ease.

Assessment of compensation awarded

In asking this question we attempted to understand the sort of process people would prefer to be used to assess the levels of compensation awarded. We had to make assumptions about which options would be under consideration. We looked at other compensation schemes to help select potential scenarios. On this question there was perhaps a predictably mixed response, however there were many comments that give a helpful insight into peoples' thinking.

Less than 10% of those answering favoured a tribunal system in isolation where decisions are made on a one-to-one basis.

Claimants should not be put through a tribunal system, they have suffered enough.

Some felt that an individualised system would best reflect peoples' circumstances but were concerned about the length of time that would take, recognising that not all the community has time on their side, some had concerns over further psychological damage ‘this process might cause’.

There seems to be more appetite for a system that at least in part involves either a tariff system (31%), a broader set of classifications (18%) or a hybrid system (31%).

There should be certain criteria for a minimum payment and then there should be an assessment part to reflect individual loss.

There were many comments advocating equal compensation for all.

A single flat rate paid to both infected and affected.

It should be a fixed amount and not decided on individual circumstances or condition. If you are affected, then the payments should be made the same

Dead or alive the payment should be the same

Some thought this should be based on the infections people had or the severity of infection and health needs.

Standard payment for each infection

Depending on the severity of illness and ongoing health problems related to infection.

It is also worth noting that a minority felt the infected should take priority over the affected in terms of both size and speed of payments.

It is more difficult to reach a conclusion on this section as there are a range of views which are more than likely powered by individual circumstances. However, there is an overriding call for fairness, which might mean equality in payments between people in equivalent circumstances. It could also reflect a desire for individuals' circumstances to be looked at in a fair and impartial way.

Perhaps this final quote sums up the key message:

Whichever method is used it needs to be prompt and efficient and not force people to dig over old ground.

Urgent need

There was almost universal agreement (96%) for the need to provide a significant up-front interim lump sum to alleviate immediate need. We know of many cases of people who are living in extreme hardship, many of whom are dealing with severe illness – either their own or that of a loved one. There are also the children of those infected whose parents have recently died who must suddenly rebuild their lives after years in a caring capacity and are having to cope with both the emotional and financial burden of their loss. Financial insecurity impacts so many aspects of life and can have devastating consequences on mental health.

A lump sum made available quickly could relieve the burden of many, including those who are elderly and have waited so long for compensation and recognition of their loss.

Yes, but must also include parents of deceased who have waited 40 years for recognition and compensation e.g., my mum who is now 94.

Eligibility and proof

We asked about proof of eligibility for compensation payments. Most people (61%) thought that if people can demonstrate they meet the criteria for support payments, then they should receive it without need of further proof. Only a smaller group (10%) thought it should be the responsibility of the individual to show on the balance of probabilities that they are entitled to compensation. Only 11% were in favour of self-assessment.

Many people commented that as they were already part of a support scheme there should be no need to prove eligibility. We know that those who have been accepted onto schemes have had to provide significant proof which has been a tough and, for some, demeaning process. Strong emotions were expressed that a simple system to transfer existing data needs to be found.

The payments should automatically be made to anyone who has been assessed already and been found to be eligible for any of the existing payment schemes. It is stressful enough having to live with the effects of contaminated blood products without the added stress of going through another assessment.

Do not ask victims to do the work here!

For those not already registered on a scheme, the prevailing comments were that they be treated compassionately and supported in making a claim. Understanding is needed where family members died many years ago or where evidence has been lost or destroyed. Any scheme also needs to provide a process for those who do not have the ability or desire to communicate electronically.

Later in the survey, 93% of respondents agreed that anyone who has been “significantly” affected by contaminated blood should have access to submit a claim.

Conversely there were some who wanted to exclude certain groups of potential beneficiaries and would prefer a restricted list of people who could claim compensation. Some rationale was given that this might speed up payments or that if there is a finite fund then limiting the applicants would mean more substantial payments to those who fall within the restricted list.

As an organisation which represents all those infected and affected with an inherited bleeding disorder directly or indirectly, we believe that anyone who is significantly impacted should be able to submit a claim and the system should be properly resourced to cope with the demands of all of those who want to apply.

We asked if people who have been impacted by viruses other than HIV or Hep C contracted via infected blood should be included in the scheme and many agreed. We know people been impacted by a range of viruses contracted through infected blood who have suffered chronic health conditions as a result. Inquiry evidence and contact with our members has made clear the psychological damage of living under the threat of vCJD. Also, being flagged as being at risk of vCJD impacts on access to dental and surgical procedures and in some cases have caused delays in treatment.

The process

We asked a series of questions about the process of application and how any review of compensation awards would be carried out. In summary, if an individual assessment is required at any point in the process, it was preferred that this be carried out by a panel of ‘experts’. Some preferred this to be led by a judge (45%) but there was a wide range of views on what would constitute ‘experts.’ The highest score was to ensure that the group includes a person who is affected or infected (91%) and it would be important that anyone representing the community acts as an advocate for all those infected and affected. The second point with a high response was to include a healthcare professional on any panel (74%) followed by a psychologist (62%). It was also agreed by the majority that any system should be inquisitorial rather than adversarial (79%).

It should be noted that this section did lead to many more comments questioning why an individual assessment should be required at all. Many would prefer not to have to go through this type of process.

Of the above I would say judge/panel however I really don't think that people should have to go through everything again.

People reiterated that any system should be easy to access, and comments suggested they would prefer a remote system so no one had to travel to attend hearings. Measures to protect anonymity would be needed, whatever the system.

A combination of remote/paper-based system depending on individual needs (not everyone has internet). It should not be at a venue as this requires travel and health issues may impact an ability to do this.

Only 3% of respondents did not believe an appeals system was necessary. However, for those people not on the support schemes, some of the more complex cases or where it has been very difficult to find documentation there may be a need for someone to challenge an initial decision and possibly provide new information. Whatever the system it needs to be easy to understand and be transparent.

Previous payments

There was clear agreement (91%) that no previous payments – such as support scheme ex gratia lump sums or pay-outs from court action – should be taken into account.

If somebody has been awarded previous payments why would they not be considered for future compensation payments?

What should compensation cover?

Our question covered general themes which have emerged from the inquiry as well as through conversations with our members. These included physical impact, consequences of treatment, mental health, loss of earnings and social impact. The overriding answer (77%) agreed that the compensation should cover these issues. Many people offered other issues that should be considered, and we received more comments on this question than any of the others.

Some of the additional themes highlighted include:

The mental impact on the individual and their family, and how in some cases their family or children have been brought into this.

Those who were financially dependent children need to be considered i.e., their loss of education and achievement and achieving their educational potential due to the effects of losing their parent.

Loss - how difficult to categorise the unnecessary loss of your child.

Many people continue to carry what they feel to be the stigma and shame of their infections in secret. Some of our members have not told people within their own family about their infections and live in fear of discovery. Some kept their bleeding disorder secret because haemophilia became so closely associated with AIDS. Whether infected with AIDS or hepatitis C, many people experienced discrimination and harassment in the workplace and within their communities.

Years of stigma as a family affected with AIDS.

Loss of income and opportunity. It is hard to calculate the loss of potential and to consider what someone might have been had they not become infected or had to care for someone infected. Many families could not get mortgages and life insurance, so had to live with long-term financial insecurity. What help was available was often seen as 'handouts' and many felt too ashamed to even apply for grants. Some were put off by the bureaucratic hurdles put in front of them. Many quite rightly resented having to go to support schemes with a 'begging bowl' for what they regarded as basic necessities.

A future has been lost, so future earnings. Also, loss of earning from a spouse due to their partners ill health impact and even death.

Handling of the tragedy. Some felt that compensation should also include government mismanagement. Others wanted recognition of the time and psychological toll the fight for justice has taken.

The personal and family costs of having to give so much time and energy to campaigning for justice because of the contaminated blood scandal.

Testing and non-consent. Many people were tested for infection without consent and, in some cases, not told the results for many years. The inquiry has heard some examples of people being used for medical research without their consent.

Longer term care and the future. People have spent their own money on issues relating to infected blood, such as IVF and psychological support. There is the uncertainty of the long-term impacts of living with infection and the side effects of treatments administered. Distrust of the medical profession has resulted in some not receiving adequate levels of care or withdrawing from the system altogether.

Many haemophiliacs, including myself, refused factor treatment when informed of infection status. I went several years without factor treatment and now suffering the consequences.

Others may not have received the appropriate hepatitis C treatment due to mistrust and fear. With so many unknowns, there needs to be provision within compensation that fully covers future obstacles and side-effects that may be experienced as a direct result of infected blood.

Just the fact we were infected, we have no knowledge of what our lives could have been only what it has been, and we have no idea on how we will be affected in the future.

What should be included in compensation package?

As well as the financial element of compensation, we asked whether there should be other aspects included within any package and over 70% of people in all cases agreed with the examples put forward.

Psychological support for all those infected and affected has been something we have been campaigning about for years. Not only is there a lack of psychological support through the haemophilia centres but there needs to be a system where anyone infected or affected can get the specialist support required.

Healthcare passporting. People who have complex health needs as a result of their infections and the subsequent side effects of the treatments they received should be given priority access, such as hepatology scans and monitoring.

GPs ignore the seriousness of the impact on one's health.

Access to dental services. People with bleeding disorders routinely experience poor and discriminatory dental treatment, which became significantly worse for those living with infections.

Teeth have been neglected for years, mostly due to the embarrassment of explaining/being greeted by people in space suits.

Many have had to spend personal money on rectifying issues caused by neglect.

I had all my teeth removed 20 years ago due to health issues with infections, implants back then were costing me £21,500.

Access to insurance and financial products. This community has been denied access to life insurance, travel insurance, mortgages, pensions and other financial products based on their past and current infection status. Where they have been able to secure such products, they have been forced to pay much higher premiums. There needs to be a system which does not penalise those living with infections and put them on an equal footing with the general population.

Financial Advice. There is a need for people to be able to access reliable and appropriate financial advice and planning. People may be affected by tax issues and other implications of a compensation package and will need free, independent and trustworthy expert advice.

Some respondents suggested access to careers advice would be beneficial.

Devolved nations

The compensation system should be a UK-wide system across the devolved nations, according to 83% of people. Parity across the four nations was paramount, but people were less concerned about the system as long as it was fair.

The infected and affected community have experienced gross inequalities in support payments between the four home nations. Some of these differences persist today, despite a long campaign for parity from the Haemophilia Society and many others. This has been extremely divisive and has left a mistrust that similar irregularities could emerge in a compensation package. It is imperative that any compensation is funded by the UK government and there must be absolute parity between England, Scotland, Northern Ireland and Wales.

Priorities

We gave respondents 3 options and asked them to name their top priority, although we appreciate that all three issues are important. They were asked to decide between speed of payment, ease of use and a chance to tell their story.

The answers were:

53% ease of use

39% speed of payment

8% chance to tell your story at a tribunal

The message from this is clear and reflects what we are hearing, people are fatigued not only from living with infections, but years of campaigning and reliving the past. There is little appetite to have another long and complicated process to reiterate what is already well known. It falls to the compensation study to find a clear and fair way for people to access the compensation they deserve.

In recognition of an urgent need for financial support, we call for a fast-track interim payment of a significant amount as soon as possible.

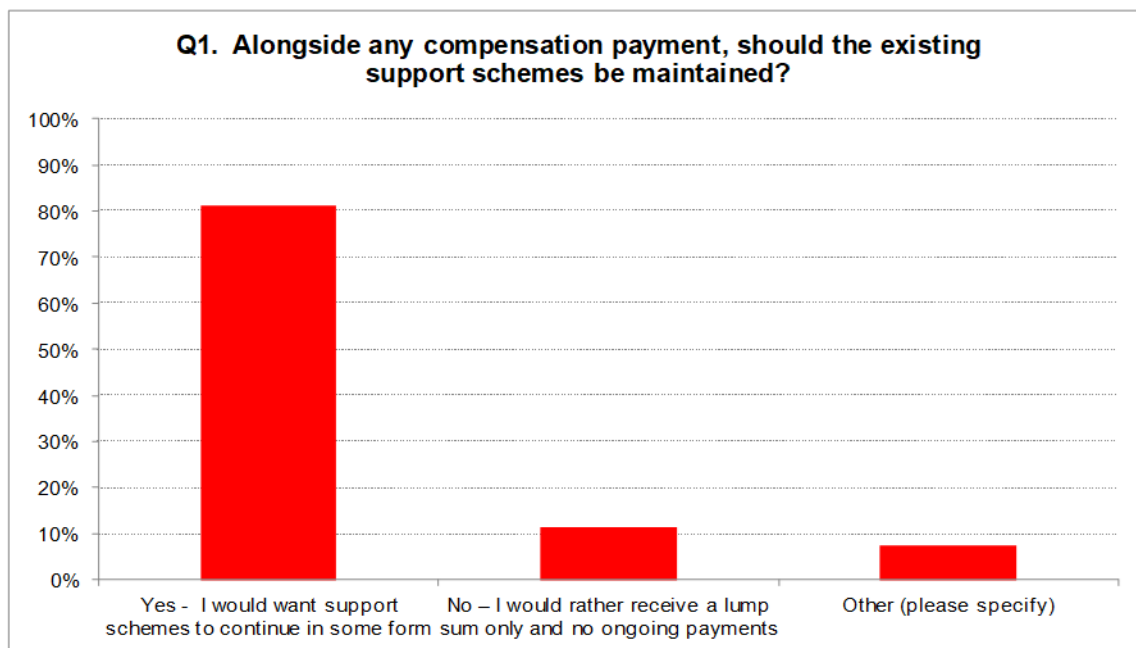
Appendix

Compensation Framework Survey Results

Question 1

Alongside any compensation payment, should the existing support schemes be maintained?

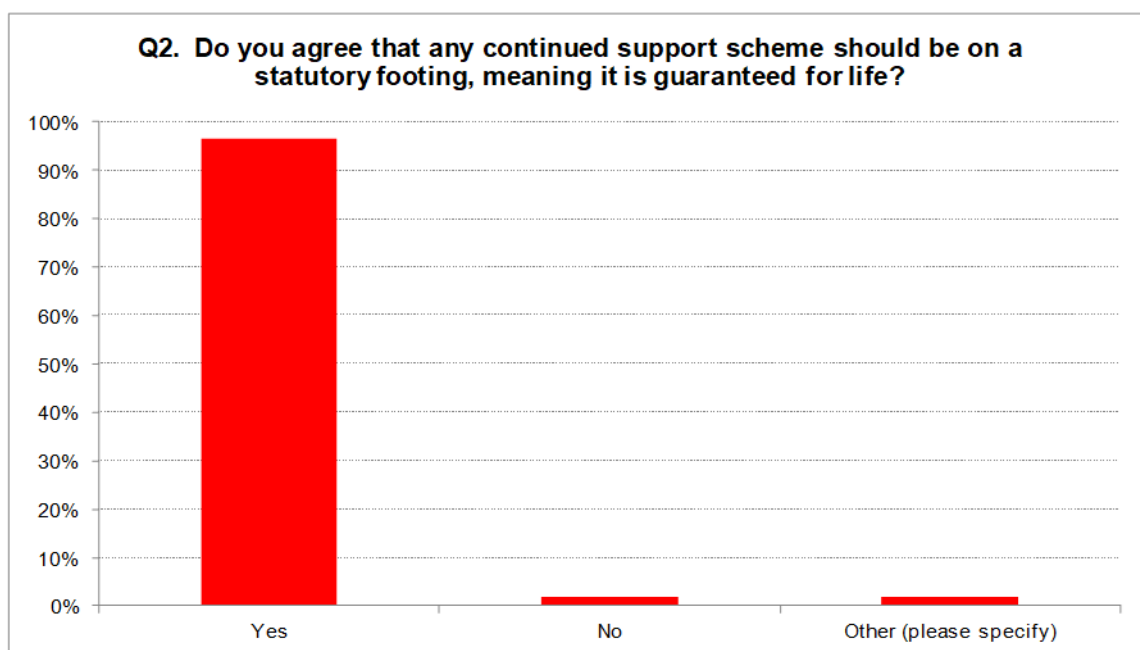
Answer Choices	Responses	
Yes - I would want support schemes to continue in some form.	81.23%	329
No - I would rather receive a lump sum only and no ongoing payments	11.36%	46
Other (please specify)	7.41%	30
	Answered	405
	Skipped	0



Question 2

Do you agree that any continued support scheme should be on a statutory footing, meaning it is guaranteed for life?

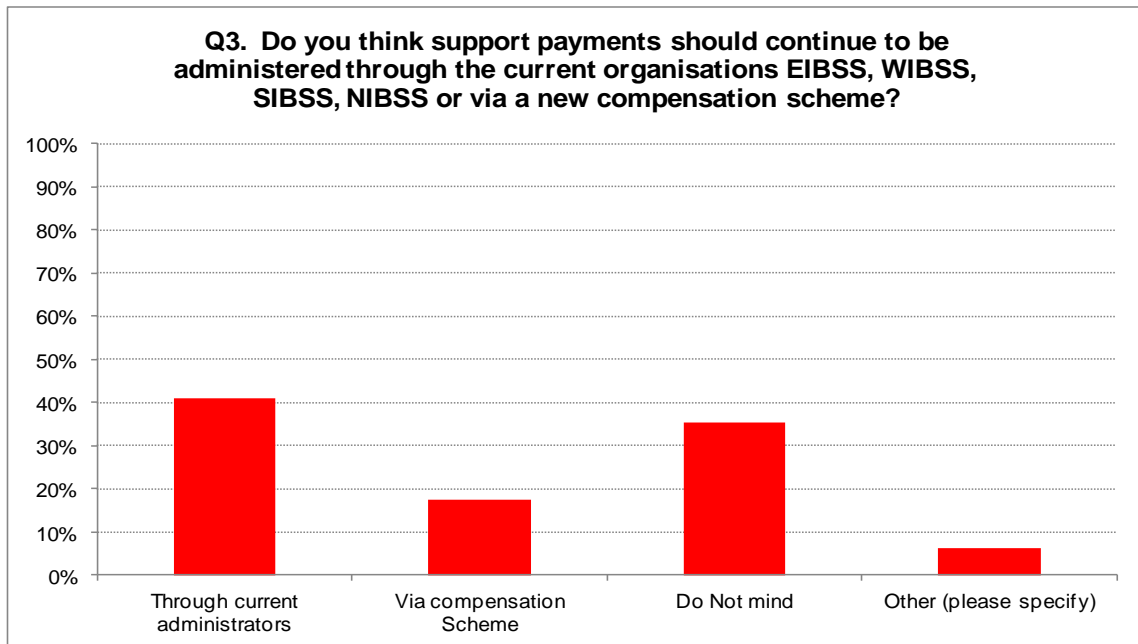
Answer Choices	Responses	
Yes	96.54%	391
No	1.73%	7
Other (please specify)	1.73%	7
	Answered	405
	Skipped	0



Question 3

Do you think support payments should continue to be administered through the current organisations EIBSS, WIBSS, SIBSS, NIBSS or via a new compensation scheme?

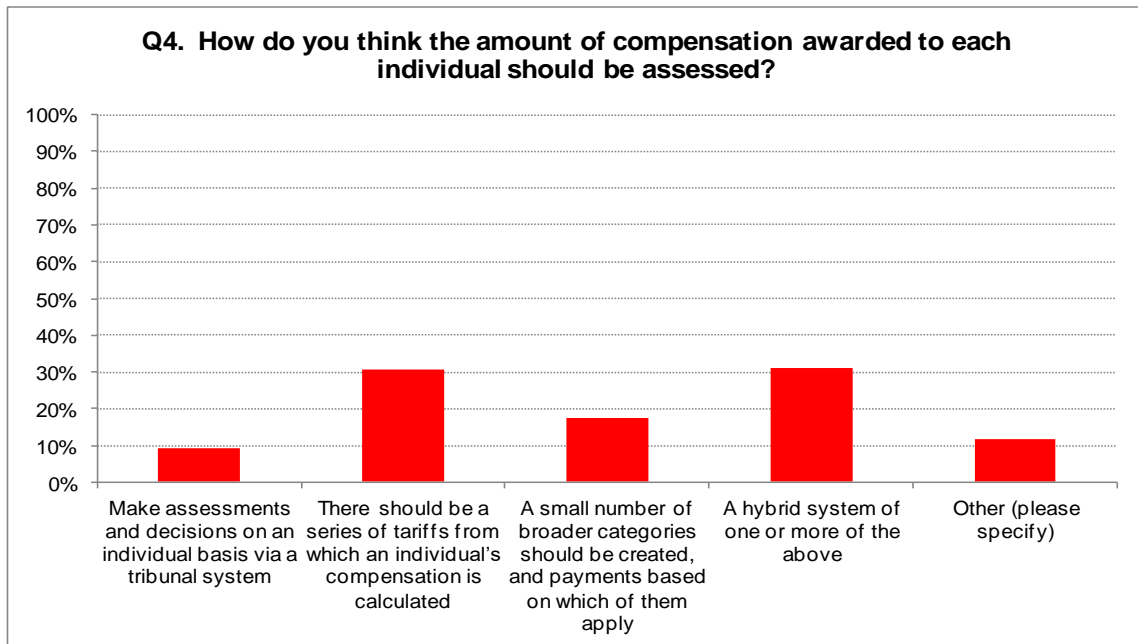
Answer Choices	Responses	
Through current administrators	40.99%	166
Via compensation Scheme	17.53%	71
Do Not mind	35.31%	143
Other (please specify)	6.17%	25
	Answered	405
	Skipped	0



Question 4

How do you think the amount of compensation awarded to each individual should be assessed?

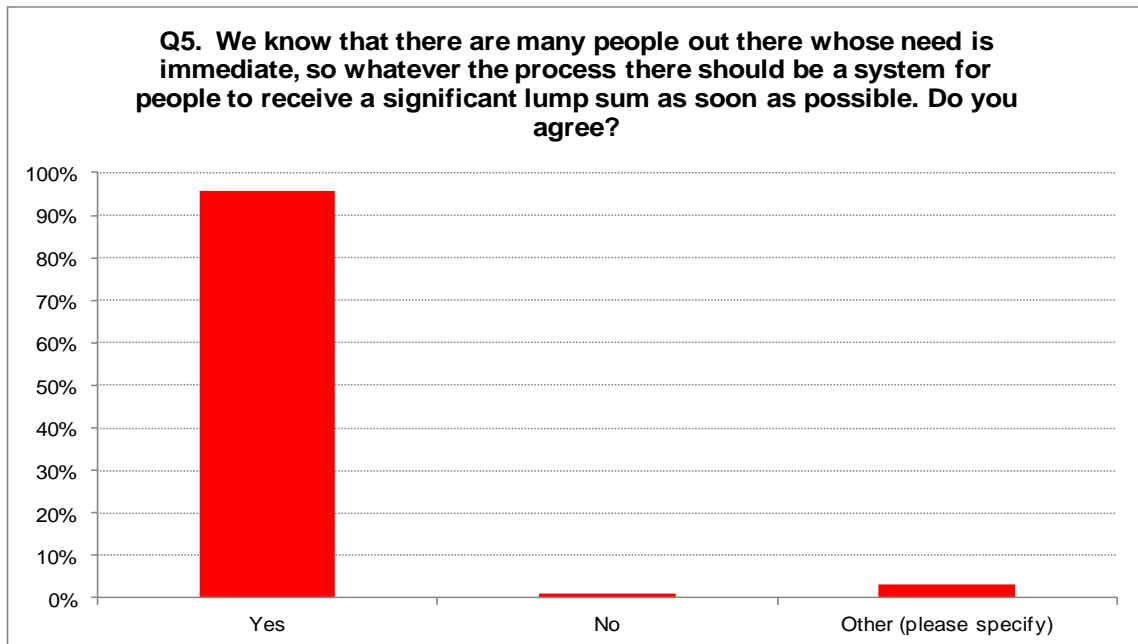
Answer Choices	Responses	
Make assessments and decisions on an individual basis via a tribunal system	9.38%	38
There should be a series of tariffs from which an individual's compensation is calculated	30.62%	124
A small number of broader categories should be created, and payments based on which of them apply	17.53%	71
A hybrid system of one or more of the above	30.86%	125
Other (please specify)	11.60%	47
	Answered	405
	Skipped	0



Question 5

We know that there are many people out there whose need is immediate, so whatever the process there should be a system for people to receive a significant lump sum as soon as possible. Do you agree?

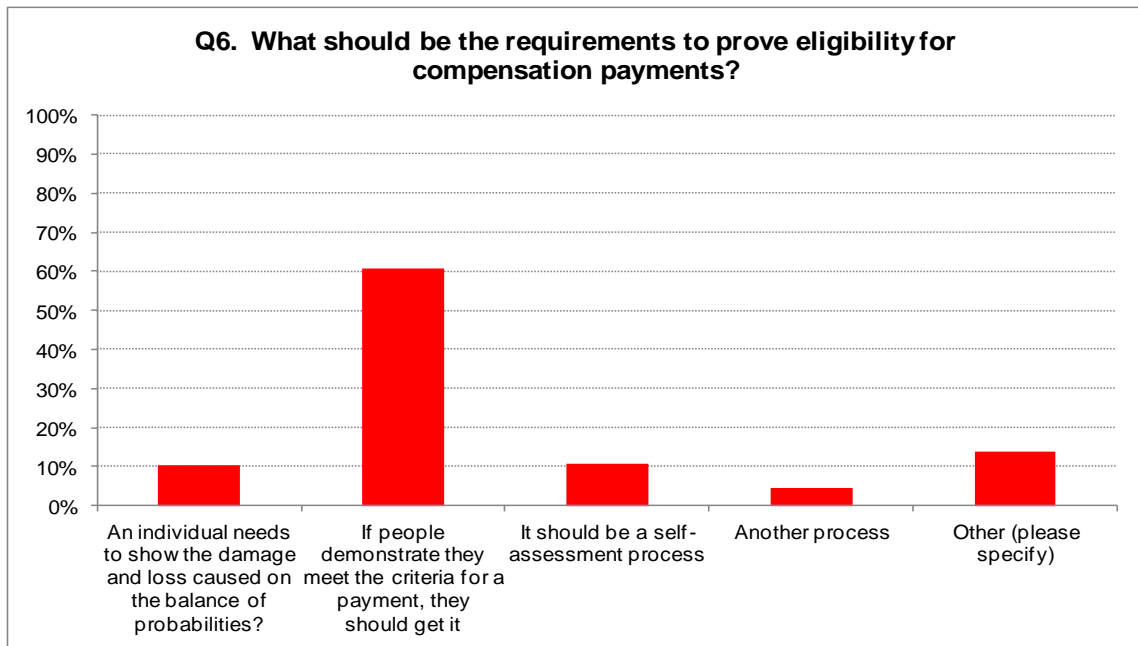
Answer Choices	Responses	
Yes	95.56%	387
No	1.23%	5
Other (please specify)	3.21%	13
	Answered	405
	Skipped	0



Question 6

What should be the requirements to prove eligibility for compensation payments?

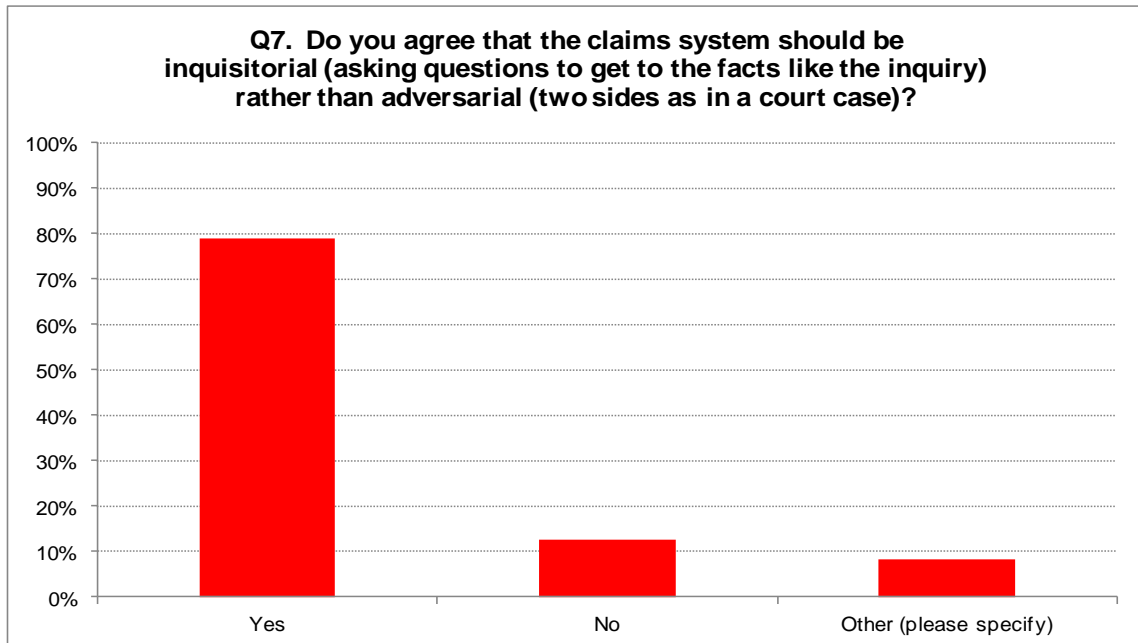
Answer Choices	Responses	
An individual needs to show the damage and loss caused on the balance of probabilities?	10.37%	42
If people demonstrate they meet the criteria for a payment, they should get it	60.74%	246
It should be a self-assessment process	10.62%	43
Another process	4.44%	18
Other (please specify)	13.83%	56
	Answered	405
	Skipped	0



Question 7

Do you agree that the claims system should be inquisitorial (asking questions to get to the facts like the inquiry) rather than adversarial (two sides as in a court case)?

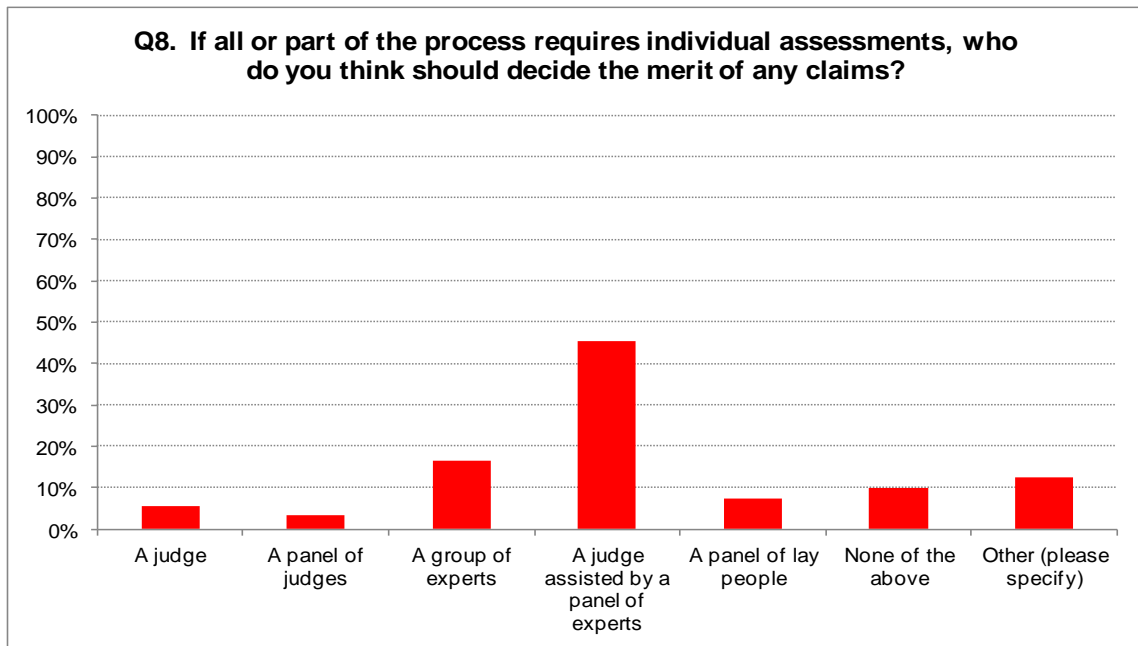
Answer Choices	Responses	
Yes	79.01%	320
No	12.59%	51
Other (please specify)	8.40%	34
	Answered	405
	Skipped	0



Question 8

If all or part of the process requires individual assessments, who do you think should decide the merit of any claims?

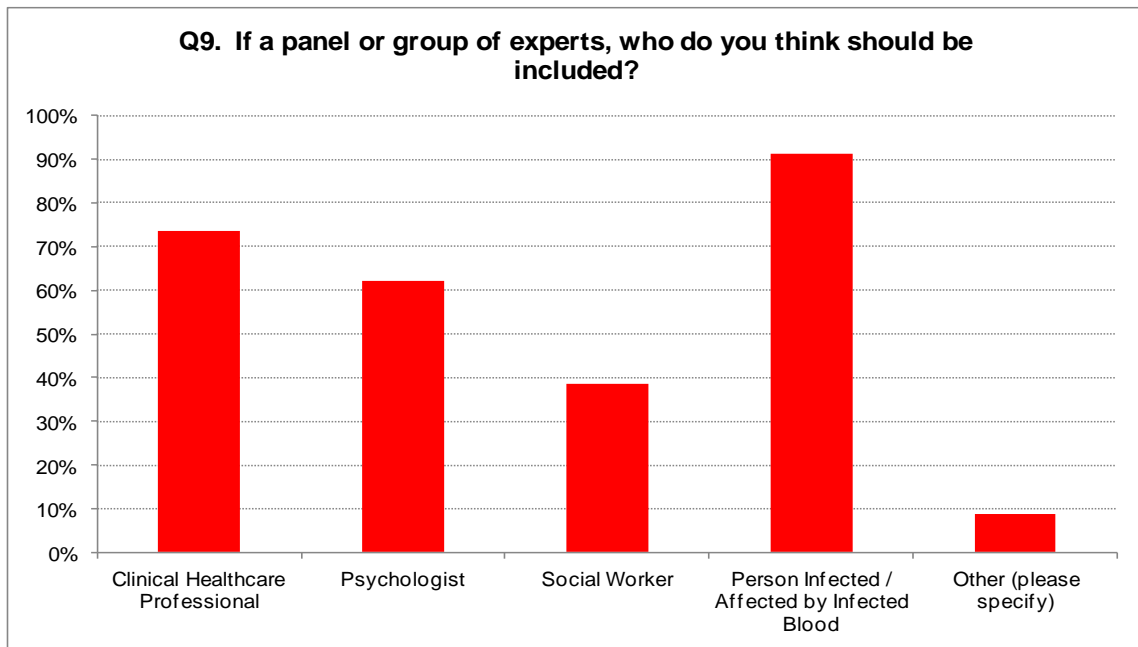
Answer Choices	Responses	
A judge	5.43%	22
A panel of judges	3.21%	13
A group of experts	16.54%	67
A judge assisted by a panel of experts	45.19%	183
A panel of lay people	7.41%	30
None of the above	9.88%	40
Other (please specify)	12.35%	50
	Answered	405
	Skipped	0



Question 9

If a panel or group of experts, who do you think should be included? (Tick all that apply)

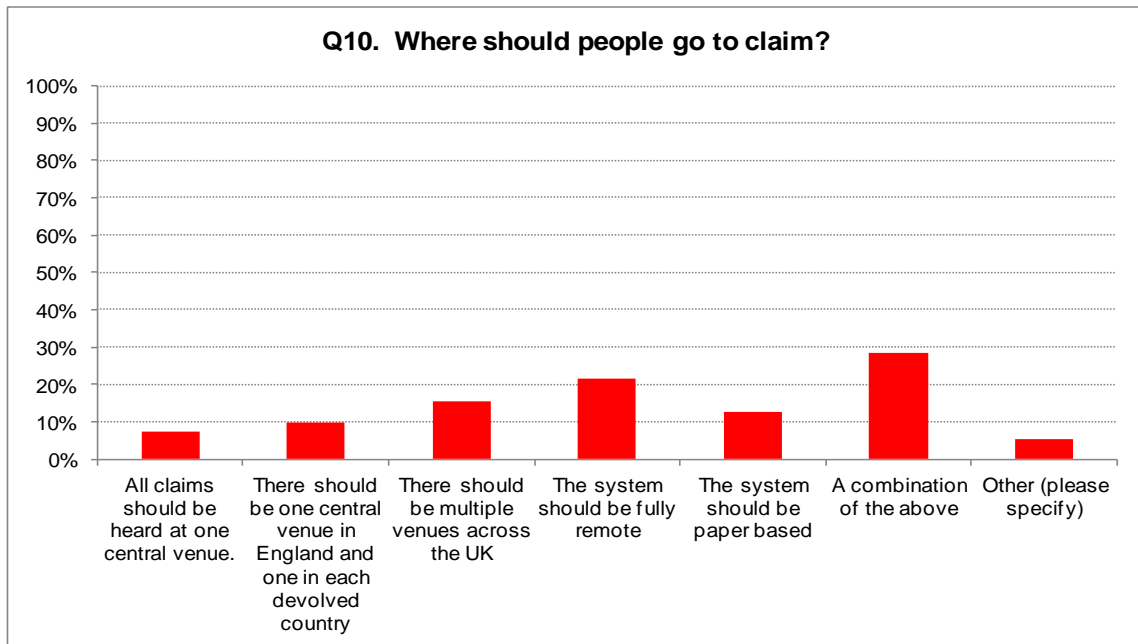
Answer Choices	Responses	
Clinical Healthcare Professional	73.58%	298
Psychologist	62.22%	252
Social Worker	38.52%	156
Person Infected / Affected by Infected Blood	91.36%	370
Other (please specify)	8.89%	36
	Answered	405
	Skipped	0



Question 10

Where should people go to claim? (select one)

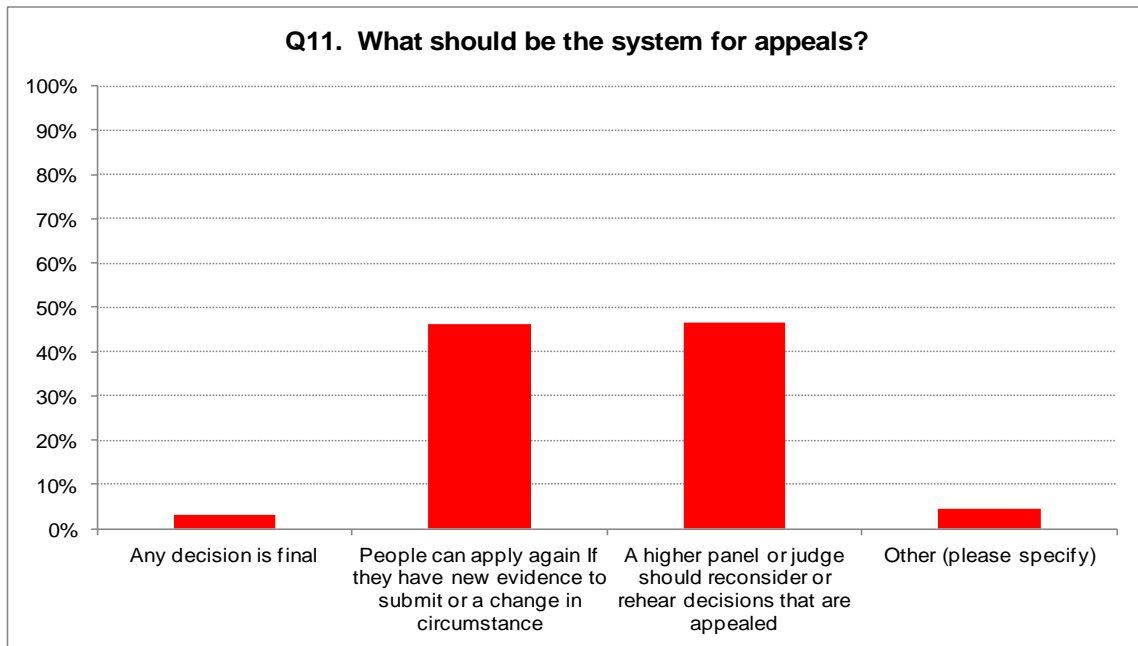
Answer Choices	Responses	
All claims should be heard at one central venue.	7.16%	29
There should be one central venue in England and one in each devolved country	9.63%	39
There should be multiple venues across the UK	15.56%	63
The system should be fully remote	21.48%	87
The system should be paper based	12.59%	51
A combination of the above	28.40%	115
Other (please specify)	5.19%	21
	Answered	405
	Skipped	0



Question 11

What should be the system for appeals?

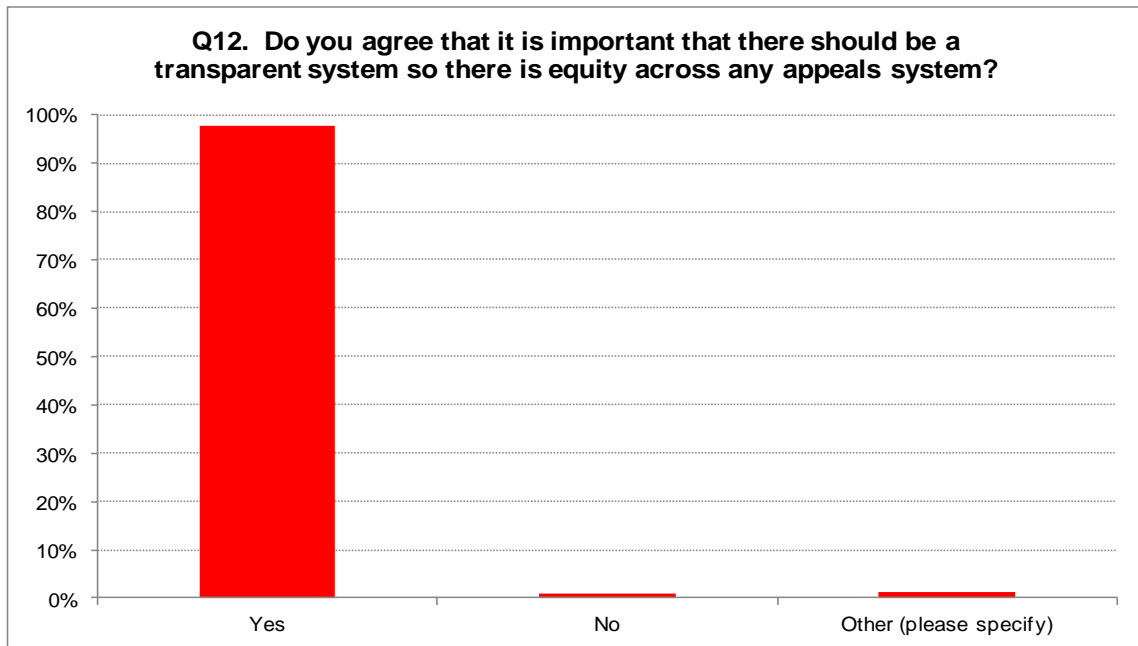
Answer Choices	Responses	
Any decision is final	2.96%	12
People can apply again If they have new evidence to submit or a change in circumstance	46.17%	187
A higher panel or judge should reconsider or rehear decisions that are appealed	46.42%	188
Other (please specify)	4.44%	18
	Answered	405
	Skipped	0



Question 12

Do you agree that it is important that there should be a transparent system so there is equity across any appeals system?

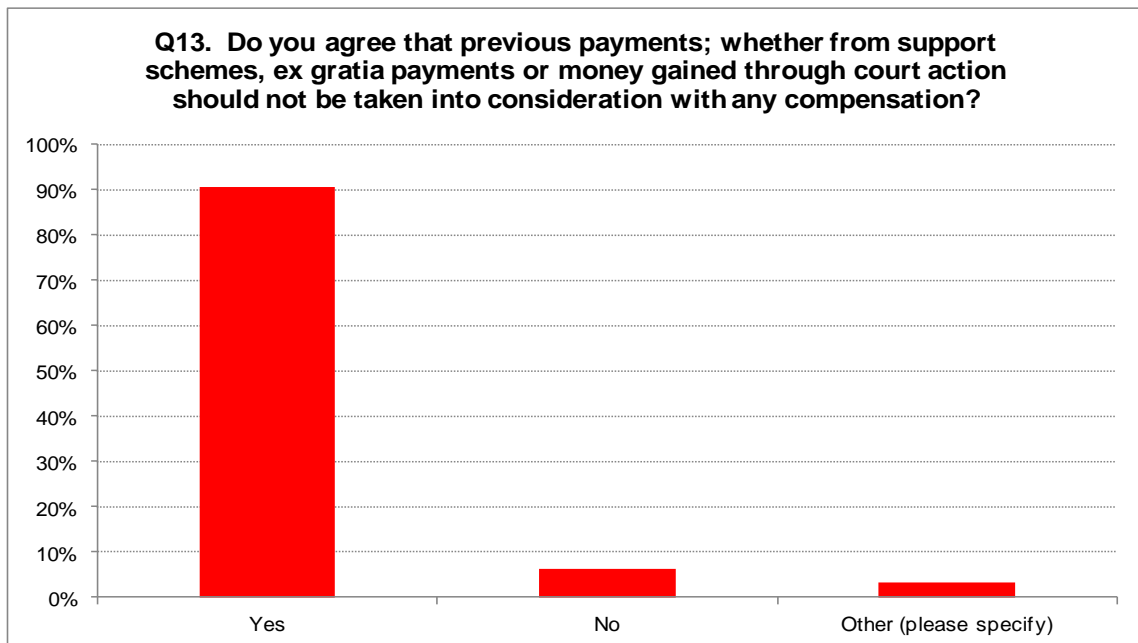
Answer Choices	Responses	
Yes	97.78%	396
No	0.99%	4
Other (please specify)	1.23%	5
	Answered	405
	Skipped	0



Question 13

Previous Payments. Do you agree that previous payments; whether from support schemes, ex gratia payments or money gained through court action should not be taken into consideration with any compensation?

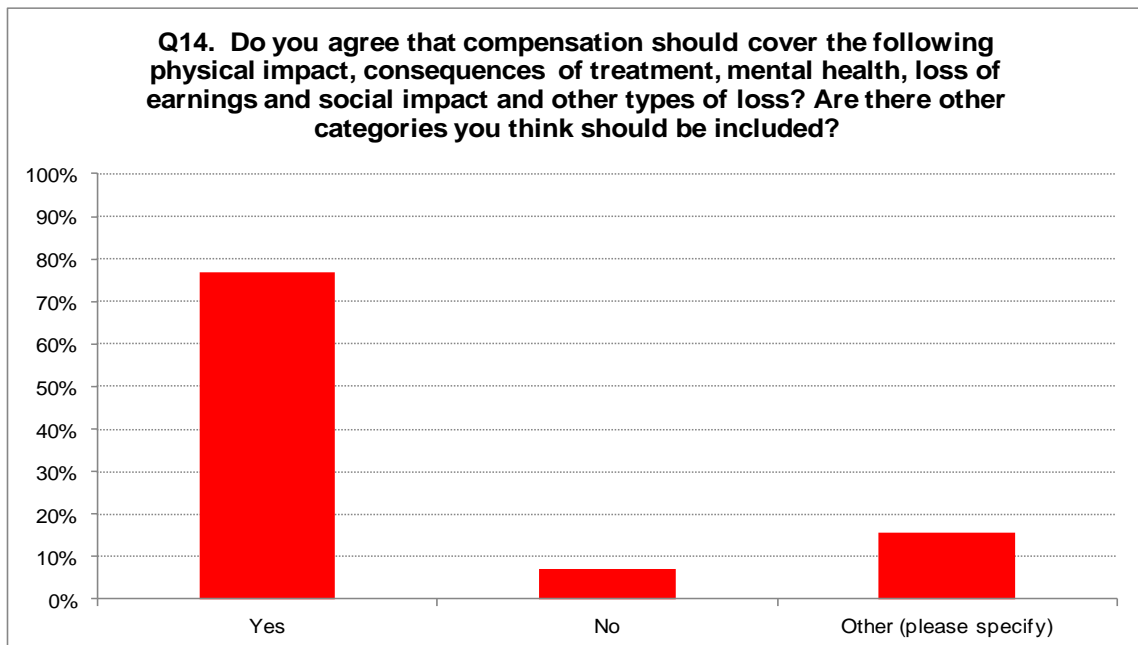
Answer Choices	Responses	
Yes	90.62%	367
No	6.17%	25
Other (please specify)	3.21%	13
	Answered	405
	Skipped	0



Question 14

Do you agree that compensation should cover the following physical impact, consequences of treatment, mental health, loss of earnings and social impact and other types of loss? Are there other categories you think should be included?

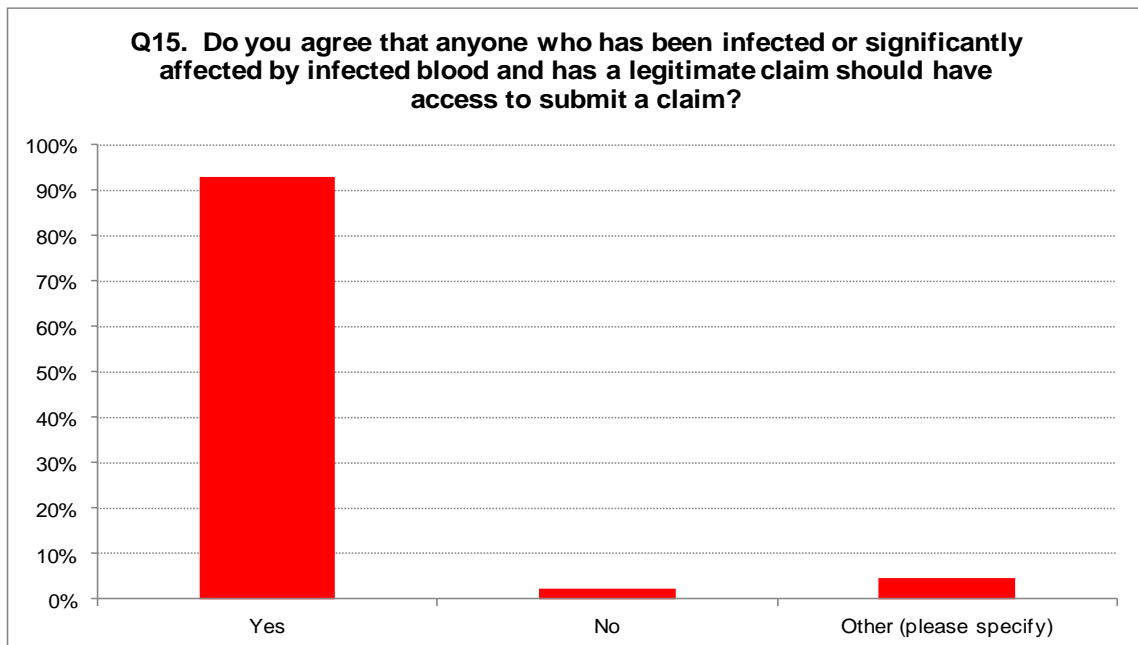
Answer Choices	Responses	
Yes	77.04%	312
No	7.16%	29
Other (please specify)	15.80%	64
	Answered	405
	Skipped	0



Question 15

Who can claim compensation? Do you agree that anyone who has been infected or significantly affected by infected blood and has a legitimate claim should have access to submit a claim?

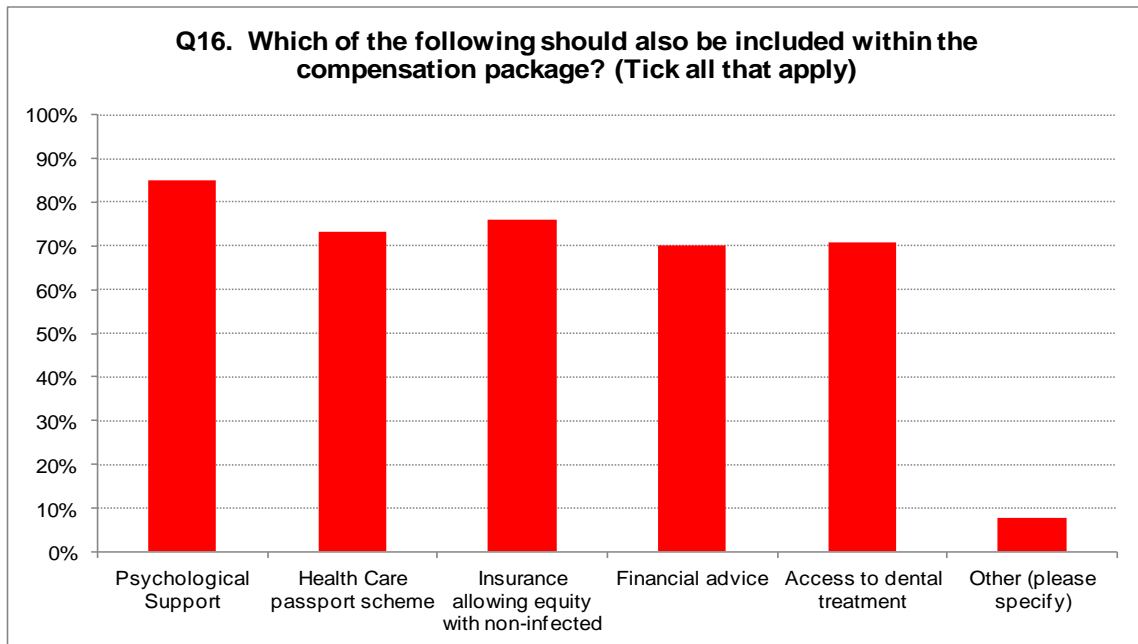
Answer Choices	Responses	
Yes	93.09%	377
No	2.22%	9
Other (please specify)	4.69%	19
	Answered	405
	Skipped	0



Question 16

Which of the following should also be included within the compensation package? (Tick all that apply)

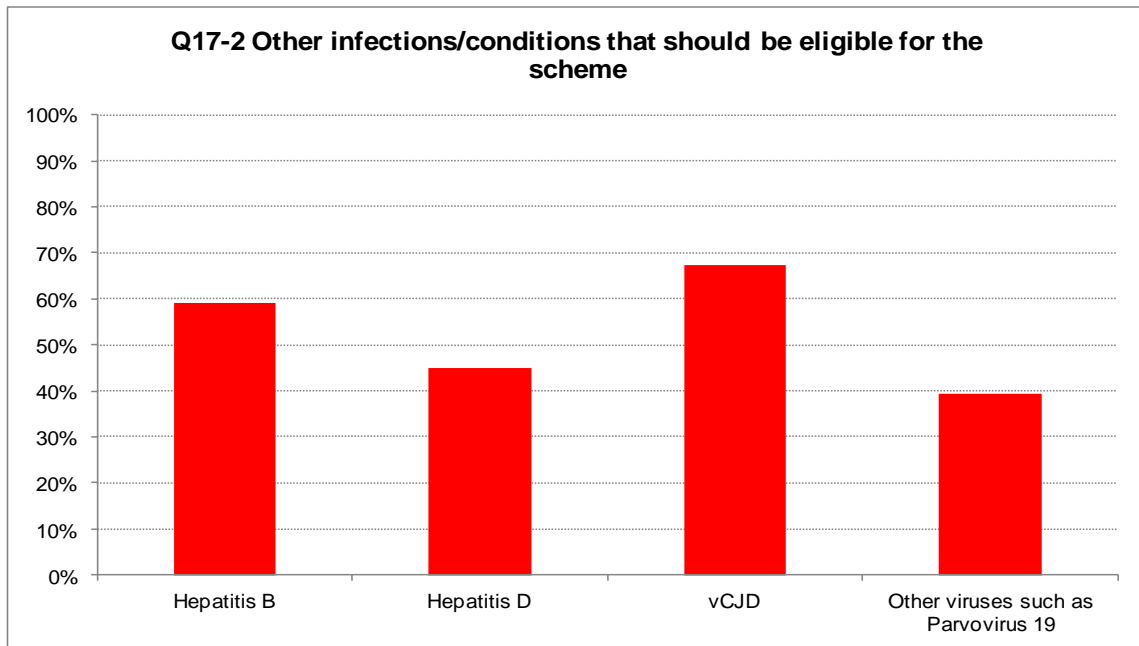
Answer Choices	Responses	
Psychological Support	84.94%	344
Health Care passport scheme	73.33%	297
Insurance allowing equity with non-infected	76.05%	308
Financial advice	70.12%	284
Access to dental treatment	70.62%	286
Other (please specify)	7.90%	32
	Answered	405
	Skipped	0



Question 17

Do you think that people who have suffered the impact of the following should be included in the scheme? (Tick all that apply)?

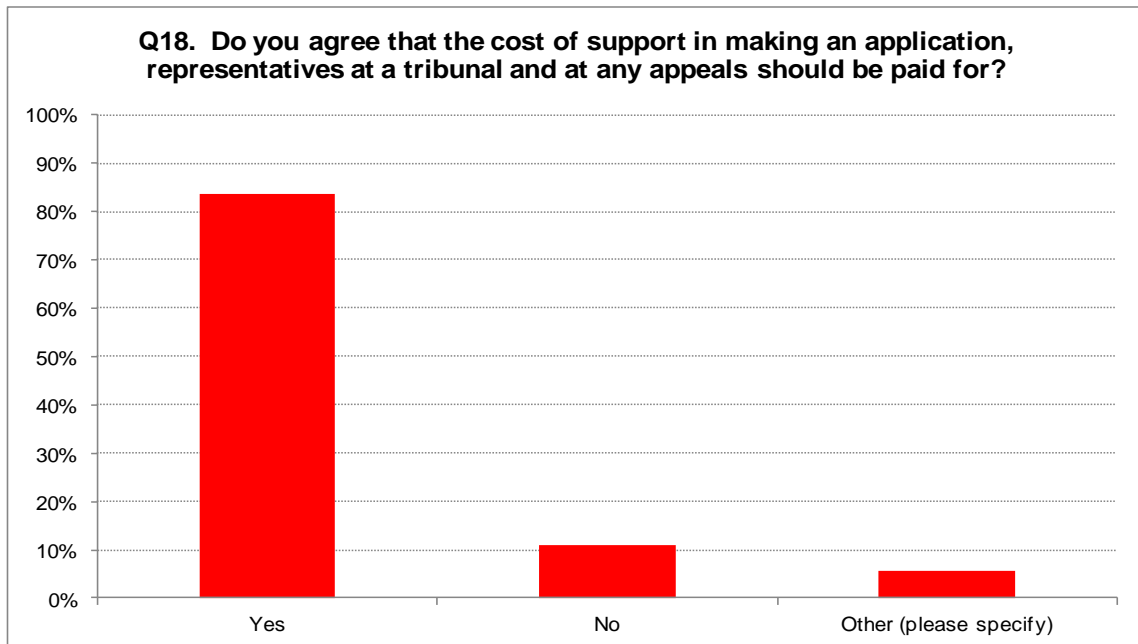
Answer Choices	Responses	
Hepatitis B	59.01%	239
Hepatitis D	44.94%	182
vCJD	67.41%	273
Other viruses such as Parvovirus 19	39.26%	159
None of the above	22.72%	92
	Answered	405
	Skipped	0



Question 18

Do you agree that the cost of support in making an application, representatives at a tribunal and at any appeals should be paid for?

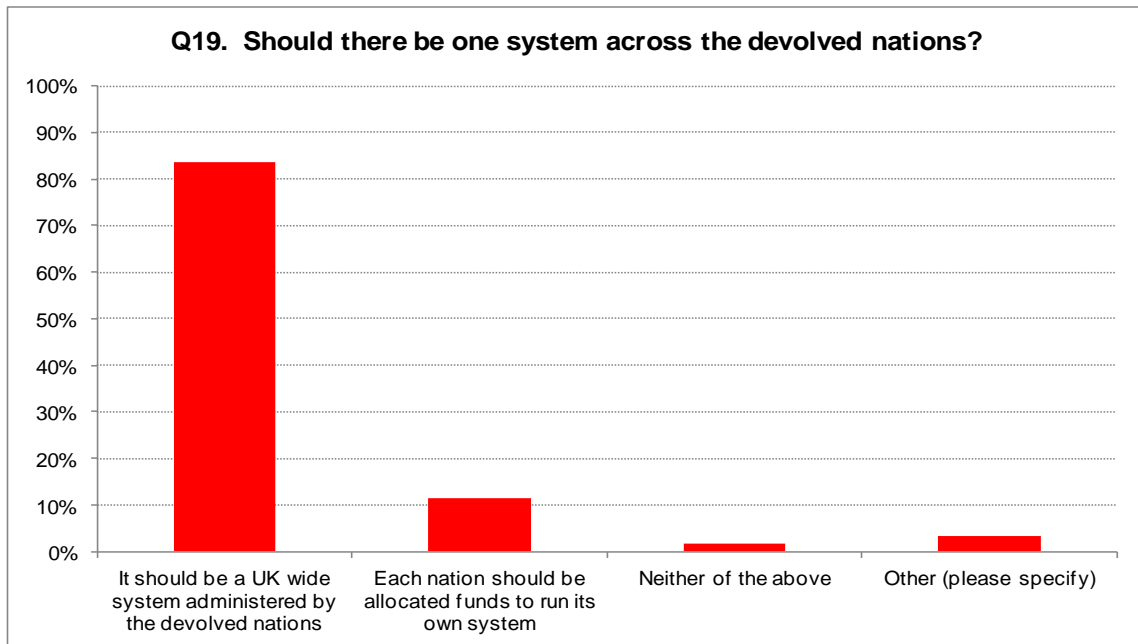
Answer Choices	Responses	
Yes	83.46%	338
No	10.86%	44
Other (please specify)	5.68%	23
	Answered	405
	Skipped	0



Question 19

Should there be one system across the devolved nations?

Answer Choices	Responses	
It should be a UK wide system administered by the devolved nations	83.46%	338
Each nation should be allocated funds to run its own system	11.60%	47
Neither of the above	1.73%	7
Other (please specify)	3.21%	13
	Answered	405
	Skipped	0



Question 20

What is the priority for you? (Select one)

Answer Choices	Responses	
Speed of Payment	39.01%	158
The chance to tell your story and have your situation examined at a tribunal	8.40%	34
The ease of the system to gain a compensation pay-out	52.59%	213
	Answered	405
	Skipped	0

