

Infected Blood Inquiry Non-financial Recommendations

**Results of a survey of Haemophilia Society
members – April 2022**

Non-Financial Recommendations

- 251 people filled out a survey for members of the Haemophilia Society in March and April 2022. Around half completed the survey online and the other half filled in paper copies which were input separately.
- All submissions were provided anonymously
- We have summarised the feedback on the questions in the survey and provided a selection of comments to illustrate the range of views.
- The majority of those responding (56%) had a bleeding disorder and were infected through contaminated blood products and just over a quarter (27%) were bereaved family members of people infected by contaminated blood products.

Are you satisfied with that apology or would you like Sir Brian to recommend that there is another apology?

Most people did not seem satisfied with the apology but many didn't think a new apology was necessary.

"Pointless as it is only words! A proper admission of guilt will never happen."

"The apology must be repeated and reinforced"

"The apology only recognises the "unfairness" of being infected but does not recognise the cover up that took place or the fact that this could have been avoided. Nor does it recognise the suffering and losses to life that this has caused."

"There needs to be a new apology accepting complete responsibility for contaminated blood products and complicit in the cover-up."

“

“I'd like sincerity in an apology”

“Yes I am satisfied, we need to move on”

Do you want it to come from the Prime Minister or someone else?

What would a proper apology look like to you?

Most people did not seem satisfied with the apology and most common was saying it should be the current prime minister as well as people who were in charge at the time and in between.

“I think current and all past PMs & Ministers for health that have been in power over successive Governments.”

“It’s the politicians and health managers of the day, those alive, that should apologise”

“An apology by the prime minister published on the front page of every newspaper and tv news station.”

“Each infected person [should be] apologised to personally”

“**Acknowledge government knowledge and failure to act.**”

“**I would not find an apology from the Prime Minister as being sincere or of value.**”

Do you want Sir Brian to recommend that the government pays for a permanent physical memorial?

Most people (51%) said yes but a substantial minority said no or didn't feel strongly about it.

"I would like to see a physical memorial located at the seats of government within each of the 4 nations of the UK. As an English citizen I would like the English memorial to be located within Westminster.."

"[A memorial would be a] focus for those infected survivors and for all affected people; and a fitting memorial to those who gave their lives."

"Personally I do not think a physical memorial is necessary but I can understand the views of others who do"

"Yes I think that would let the population know what suffering [the contaminated blood scandal] caused, and still is."

“

“Yes, so that there is always a reminder”

“To what end? Again, it doesn't help people move on.”

Do you want Sir Brian to recommend an NHS health passport that gives priority to everyone with a bleeding disorder infected by contaminated blood and blood products, so that they go to the front of the queue for the best possible NHS monitoring, investigation and treatment?

The majority (77%) of respondents said yes but some added conditions or said it was difficult to justify.

“There are many other groups of people that this could apply to so to make special case for one group could be hard to justify “

“For relevant conditions or investigations, yes - but not for non-related things. The NHS has enough pressures without having that kind of thing applied too.”

“I don't believe there should be queue jumping but people who are co-infected should be monitored at regular intervals as they are at increased risk of developing liver problems

“ If we have something wrong with us we should be seen as soon as possible”

“Everyone should take their turn except for an emergency”

Do you feel you are getting the information you want and need about your treatment and its risks and benefits?

Of the people to whom this question applied the majority (59%) said Yes but many respondents raised concerns.

“My haemophilia centre is very good. I have a check up every 6 months where treatment options are discussed . This is sufficient”

“Cascade of info is limited, with regards to success of trials. Haemophilia centres need to improve communications to patients.”

“

“Unfortunately no”

“I was never consulted. I was told what treatment I was being put on.”

Do you ever feel pressured to agree to new treatment or a change of treatment?

Most people said No but around 15% said Yes.

“This has happened to us recently, [we were] changed to a PEGylated product without consultation”

“In the past yes, when current treatment became unavailable I was switched to a cheaper one. I was very lucky I avoided infections. It is better now and I am more empowered and informed.”

“I’m just told what I’ll now be getting.”

“[My son is] now grown up making their own choices. Previously [we were] pressurised but on occasions my wishes were respected. But one needs confidence to be assertive and ask many questions “

“

“I just take what the doctors are saying is best”

“No this has never happened to me”

Do you have any fears that your treatment may not be safe?

Of those that had an opinion a small majority (57%) said Yes.

“I know that there may be risks as yet unknown (CJD, Viral) and risks with recombinant proteins I accept that very small risks are outweighed by the benefits of treatment”

“Yes, because of historic problems, when new treatments become available, one is concerned how safe it is.”

“Not now that treatment is fully synthesized.”

“That’s always on my mind, but they do explain all the filtration systems it goes through.”

“I think the boat has sailed on that one, so it does not bother me anymore”

“Lessons have been learned”

“Time will tell. It could be a risk”

“I have a morbid fear of all blood based treatments.”

Have you ever made a treatment request and been turned down? If so what was the request?

Just over one in ten respondents said yes and mentioned dental care, psychological support, liver health monitoring, physiotherapy and colonoscopy.

“ [I was] told to find my own care in the local community when from a psychological perspective I preferred the anonymity of hospital provided care. There have also been cost issues around providing facial filler treatments which again would be beneficial psychologically.”

“It was for psychological support for my son post bereavement, but that is now available.”

“ I asked for the new treatment Hemlibra and was refused”

“[It] never occurred [to me that] you could do that”

When your doctor gives you medical advice and information, do you understand what they are saying?

The vast majority (72%) said yes but 7% said no.

“Yes, however I have my reservations about getting the real reasons for changes i.e. was it financial or more beneficial?”

“Generally if I don't understand I tell them and ask them to explain further.”

“You should ensure you fully understand what the doctor is saying. The doctor has a duty to ensure the patient understands what they are saying”

“I do now, but it hasn't always been that way.”

“Now they spend a lot of time explaining everything, and you are always asked later if there is anything that you are concerned about. I do wish that had been the case almost forty years ago when I was under 16.”

“

If I don't I ask and clarify and do my own research”

“I do but always take partner with me for a second set of ears just in case”

Do you ever worry that because you have a bleeding disorder (or your child has one) you (or your child) is being used to further medical research?

Around one in five said Yes.

“I accept that I have a rare condition and further research will benefit future generations or even my own treatment I am keen on this”

“I feel that the ethical approval of research is now more closely monitored.”

“Not doing medical research is tantamount to burying your head in the sand. But it must be clearly explained”

“As far as I’m concerned this never happened to me. If I found out it was or became suspicious I would be furious.”

“

Happy to further medical research as long as I am aware and not put at further risk.”

“Yes in the past but not anymore.”

Have you ever been involved in a clinical trial of a bleeding disorder treatment, or agreed to enrol your child in a trial? Did you have any concerns about what happened during the trial?

Most had been involved with trials but experiences varied. Most people were happy with how trials are run now.

“Trial was well monitored and I was removed when problems occurred.”

“I enrolled voluntarily, or at least to the ones I know about”

“I don't worry about it, I willingly took part in a trial... Research is the key to better future treatment and understanding”

“
My blood and tissue was used many times of which I was not informed or my parents.”

“[I was] fully and well advised at all stages during the trial.”

Do you ever worry that if you complain about a doctor or about an aspect of your care that that might jeopardise your future treatment?

A substantial minority (28%) had worried about it.

“I suspect I would think twice before complaining in case it jeopardised my care. I would hope that I would not need to though.”

“I find the medical profession take criticism badly and do not demonstrate humility to place the patient at the forefront of decision-making.”

“I appreciate good care but do openly say if care has been poor or inadequate. This has been relevant on several occasions “

“
[I am] not really worried, I feel assertive enough to express an opinion or complain”

“I wouldn’t [complain] in case it did [have an impact] in the future”

Have you ever experienced problems with communicating with your doctor or health practitioner?

A substantial minority (29%) had experienced problems.

“When first diagnosed my GP initially refused to accept my positive Hep C result, denying I actually had it!”

“Doctors are not good listeners. They would be much better listeners if my debit card was poking out of my top pocket”

“in the past ... but not now“

“
There was no communication regarding Hep C”

“No, my treatment at [two different centres] has always been excellent”

Do you want Sir Brian to recommend that there should be guaranteed access for all people with bleeding disorders to recombinant products?

The vast majority (86%) said yes.

“I have been on recombinant products for 10 years plus and consider that all patients should have this”

“The best treatment should be given to each patient regardless of which bleeding disorder or condition they have “

“After everything that has happened, people must surely be fully entitled to products that offer absolute security and peace of mind”

“Yes because I’m Von Willebrand's type 3 and we’re still on plasma based treatment “

“ If we are all treated the same then we will sooner all feel like survivors instead of victims”

“The optimum treatment should always be available to every patient”

In the past access to new treatments was held up due to costs. Do you want Sir Brian to recommend that there should be guaranteed access for all people with bleeding disorders to new therapies including gene therapy, if deemed clinically appropriate?

Almost everyone said yes (91%) but some added provisos.

“I don't think we can ask for this as all medication should be subject to a cost benefit analysis. The NHS is not a bottomless pit and decisions sometimes have to be made on cost.”

“Yes, I think the clinically appropriate line is very important here but there should be fair and reasonable access for everyone “

“ Ideally yes, but appreciate funding will be an issue going forward.”

“Cost must never be a factor in treatment”

Would you like Sir Brian to recommend that all trainee doctors and nurses are required to be taught about the contaminated blood scandal?

Almost everyone (92%) said yes.

“They should be taught to consider the potential impact of their actions in any prescribing they do. Otherwise problems like the [contaminated blood scandal] could occur again.”

“It would give them context and increase sensitivity“

“I find it hard to believe in the modern era that anyone going into the medical profession has no knowledge of the infected blood scandal, but if this is the case then they should all be made aware of it”

“**Yes definitely, it can only be beneficial”**

“Yes so that they can learn from mistakes and [make sure they don't] happen again”

At the moment, training on advanced patient communication skills is optional for doctors. Do you want Sir Brian to recommend that such training be mandatory?

Almost everyone (89%) said yes.

“Everyone has the right to be communicated with properly by medical staff, not just people with bleeding disorders, I can't believe it's not mandatory already”

“Communication skills are fundamental to good medical care. This involves listening just as well as telling.”

“[This should be] mandatory training for all healthcare professionals. An appreciation of a patient's perspective and understanding is vital”

“
Of course, this is
essential training.”

“It should be
mandatory. I'm
surprised it is not”

Are you confident that medical information about your condition and treatment is confidential to you, and that it isn't shared with anyone else unless you agree?

The majority agreed but a substantial minority (22%) still had concerns.

"I am happy with how the centre I attend handles personnel information now. However I am not confident it applies to all areas and centres"

"Now we get asked if medical information can be shared. I don't have an issue with this so long as I know what and why it's been shared."

"It's not clear to me what my rights and expectations should be in this area. Are there circumstances in which details might be shared without my knowledge or consent? This has never been discussed with me."

“ [I am] confident now, maybe not so much looking back.”

”I think I am now. But certainly wouldn't have been 40 years ago.”

Do you ever worry that information about your bleeding disorder (or your child's bleeding disorder) might be shared with pharmaceutical companies without your knowledge/agreement?

Most people didn't worry but a substantial minority (23%) still had concerns.

"Current ethical guidelines and privacy law means that this should not happen now. This was not so in the past."

"We need to share data to find new treatments. It is normally anonymised"

"It's my confidential information and shouldn't be able to get used without my knowledge or permission"

“

These things always cross your mind, but how would you ever know“

”[I have] no major concerns with this”

Are you confident that when you have a blood test, you know what is being tested and why?

Many people (28%) didn't know what they were being tested for but comments suggested this wasn't a cause for concern in most cases.

"I don't normally ask what is being tested as I trust it is necessary."

"They often take tubes. I sign lots of forms [but] don't want to hear long answers"

"I always think I know what the principle reason is - but I have no control whatsoever over what is actually tested as well - or why"

"Over the years I have learnt what the various titles and name of the tests are and if there is something new I ask what it is"

“

I never really know! I just give it and that's it“

” Perhaps because of historic use of blood samples, I have lost faith in the system.”

Would you like Sir Brian to make a recommendation that you get written information about how information about your bleeding disorder and/or blood related infections is held and used?

A majority (66%) wanted this.

“I think patients should hold their medical records, so that they retain control over who sees them, so they can give access to them at any healthcare facility if they wish, and so that they can contribute their own notes about treatment and symptoms etc.”

“I can ask for this anyway - so not sure why a recommendation is needed. I don't want the NHS to have to write to me every now and again to tell me this - it's a waste of resources.”

“
It would make sense
to know”

Have you ever been on the receiving end of hurtful remarks or discriminatory treatment from the NHS as a result of being infected with HIV or hepatitis C?

A substantial minority (28%) have experienced stigma or saw care and treatment withheld or restricted.

“I have always kept very quiet about [my infections], for fear of being stigmatised”

“I have had remarks from people I know, [but] not the NHS that I can remember. [I overheard] remarks about being diseased... [It] increases my anxiety a lot. I have always feared people knowing.”

“[My] NHS Dentist kept unregistering me. This isn't an unusual experience within our community“

“**Too many to list but usually due to ignorance of general public and medical staff.**“

”**[I was] made to feel very uncomfortable [by] staff not really wanting to treat you**”

Have you ever been discriminated against or treated poorly when accessing surgical or dental services?

A substantial minority (27%) felt they had been discriminated against.

“I have suspected they spoke amongst themselves about it. I hated going to the NHS dentist on my town, a trainee nurse told people in town about my situation. [It was] anxiety inducing and distressing.”

“Many NHS dentists won’t take infected persons. We were told it involved too much time for sterilisation of everything.”

“[I was] told I had to wait till the last appointment of the day and to use “the old colonoscopy” scope as I had received treatment from someone who had donated blood with vCJD.”

“

One dentist did not want me as they said they could not reuse equipment.”

“I used to be treated in a separate room with a lot of over the top PPE and equipment used”

Have you ever been made to feel that because you have a bleeding disorder you are a burden on the NHS? Or that you should be grateful that the NHS provides you with expensive treatment?

A minority of people (24%) had been made to feel this way.

“Comments about cost of treatment have been a lifelong theme. I bet that doesn’t happen to oncology patients!”

“Yes, some doctors have made throw away comments about how much treatment is, although this was 30 years ago, not now.”

Have you ever felt under pressure to agree to a certain type of treatment on cost grounds because your preference for a different treatment is greedy or selfish? Do you feel that is the case today?

A small minority (12%) still felt this was the case.

“Only when I was a child. It was suggested that it might be good idea not to reproduce.”

“I have been asked in a roundabout way to take a cheaper alternative.”

Would you like Sir Brian to make a recommendation that prevents government from imposing waivers on vulnerable groups suing the government?

The vast majority of people (86%) agreed with this recommendation.

“There should be no need for waivers, governments should simply accept responsibility for mistakes made”

“I think many of us feel that not only are such waivers unfair, but that we were both lied to and pressured in signing this, which is wholly unacceptable.”

“

Absolutely!”

Would you like the power to decide about when to hold a public inquiry to be taken out of the hands of government and given to an independent body?

Most people (80%) agreed with this recommendation.

“In this day and age, especially if it is something the government has done, an independent body should be given this to sort out.”

“The Government itself may be responsible for an event. They should not have the power to stop such an inquiry.”

“Public Inquiries are expensive and lengthy Whilst it is right and proper in this case I do not think they are of benefit in all cases and do not want an independent body to result in too many inquiries”

“

“Damn right - keep politics out of issues that can have a profound impact on a subjects health and lives”

Do you want Sir Brian to recommend that research should be funded to look at the long-term impacts of living with HIV/AIDS and hepatitis?

Most people (89%) agreed with this recommendation.

“Unless you study this how will you know how to go forward with this. Lessons need learning from , so processes should be put in place to assist people in their care.”

“This needs to cover the impact of treatment for Hep C“

“Other research topics suggested included, anti-viral treatments, gene therapy, PEGylation, vCJD, inhibitors, women and bleeding disorders and fertility.

“
This should be happening anyway for the benefit of everyone living with the conditions”

Do you want Sir Brian to recommend that there should be access to appropriate social care to support people living with the impact of infected blood into old age? What kind of social care would you find most helpful?

Almost everyone (93%) agreed with this recommendation.

Examples of support included personal care at home, home improvements, psychological support and counselling.

**“
Many people within
our community will
definitely need
support as they
reach old age and
the infections and
treatment for
infections mean that
many are ageing
faster”**

Do you want Sir Brian to recommend that the Haemophilia Societies across the UK and charities working in this sector receive funding to continue their support of the infected and affected community?

Almost everyone (90%) agreed with this recommendation although a small number thought other groups should have this funding instead.

“This should be a lasting legacy, this would enable them to continue to support people that have been affected and this should include their families into the future.”

“I would also include long term campaign groups in any government funding. If it wasn't for the community and campaign groups we would never have achieved all that we have to date.”

“It can't just stop, people are relying on their help and support”

**“
Absolutely! Who will
protect and defend
our community in
the future if it is not
the Haemophilia
Society.”**

Although Sir Brian can make recommendations that is all they are and so someone appointed to follow up on actions to ensure they are put into practice could be beneficial to the community. Do you want Sir Brian to recommend that a Special Advocate for the infected and affected is appointed to ensure that recommendations from the inquiry are implemented?

Almost everyone (89%) agreed with this recommendation.

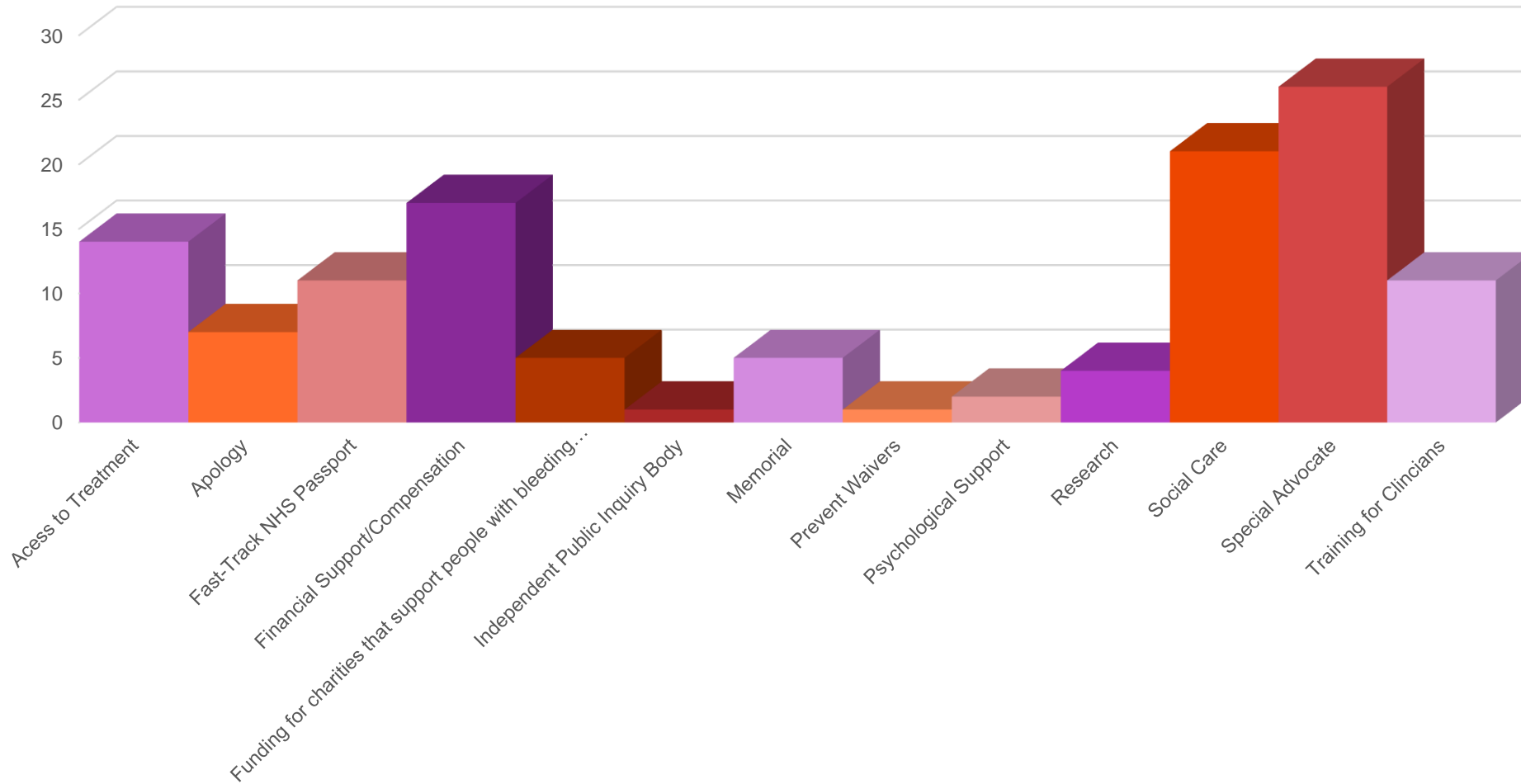
“Otherwise these issues can drift.”

“This has to be the case otherwise the Government will conveniently forget about any recommendations Sir Brian makes”

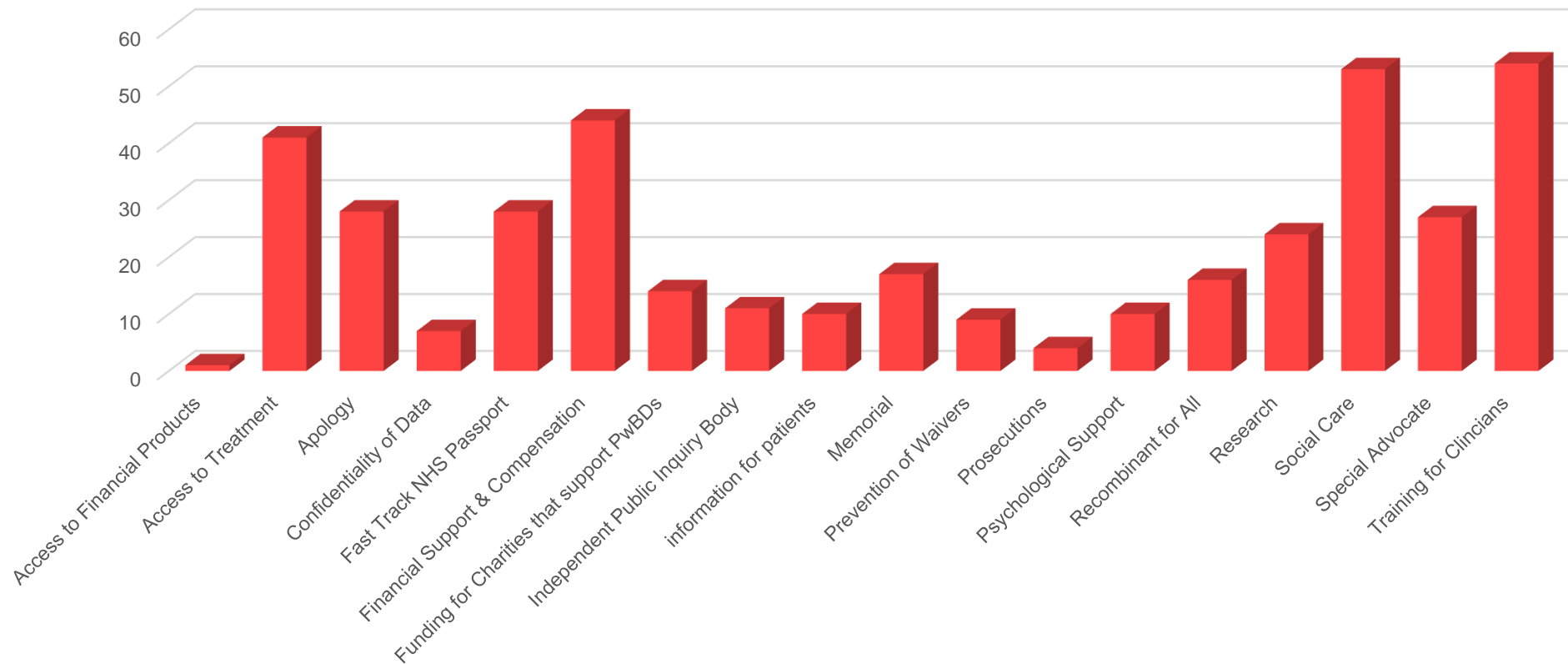
“Definitely THE GOVERNMENT CANNOT BE TRUSTED.”

**“
Essential. There are numerous examples of recommendations form historic Public Inquiries that have not been implemented”**

Which one of these recommendations is the most important to you?



Top 5 recommendations



Members were asked unprompted to list their top 5 priorities for recommendations. The chart shows cumulative totals of the recommendations mentioned