

SUBMISSIONS FROM INDIVIDUAL COLLINS CLIENTS

	Submission
1)	Well my husband died 34 years ago and was co infected hep b hep c and hiv. I am 70 years old this year. They can pick the bones out of that. All the lies on oath about working at pace ? WHEN THEY were doing Nothing ! It's diabolical.
2)	"While I welcome the need to reform the compensation process, I am concerned that the outlined scheme will push the estate of the deceased and affected widows, who are registered with schemes such as EIBISS and already in the system, further down the list and result in further delays to their compensation. My father died in 1991 from Factor 9 concentrated which was contaminated with HIV. My mother is his widow. She is registered with EIBISS, who have all of her, and my father's records. She is now 81 years old. According to the scheme that you have outlined, as an affected widow and as the beneficiary of my father's estate, she will be pushed further down the queue, behind people who are not part of any scheme and will have to wait until all of those quite complex cases, involving lots of evidence gathering, are completed. She will also have to wait even longer to receive what is due to her as an affected person. She is elderly and very distressed that these further delays will mean that, if she does get the money before she dies, it is increasingly likely that on her death, 40% of that money will have to be paid back to the government in inheritance tax, when the compensation money should have been paid out to my dad's estate 34 years ago, and the financial loss to her had also been going on over that period of time and not just now. This seems to be just another injustice meted out to her among the many over all of these years."
3)	I am a bereaved partner and have stage 4a ovarian cancer. I definitely won't be here in 2029, or possibly end of 2025. I note in their update they will expedite the terminally ill for the Infected. They must see that if they don't include the terminally ill Bereaved to run concurrently then starting the Affected at the end of this year will rule them out as they will be dead! I will only be doing the Core route I think so my case should be relatively easy. If not, is it not feasible to do an interim payment, particularly because the Affected cannot pass on compensation to next of kin (unlike the Infected)? The death of a person contaminated is the ultimate price they paid; my XXX was only 33 when he died. My MP, XXX, brought up my case today in the Commons with the Paymaster General, so is very supportive of me. I know IBCA said deviating from their plan would cause delays but it must be feasible as am sure they have the abilities within their team, if they are instructed, to do so.
4)	<p>I think regulations could be adjusted to recognise the concerns being raised by haemophiliacs. Non-HIV haemophiliacs are talking about litigation, the thought of that terrifies me. I am a severe haemophiliac, aged 60, infected at 7 months, on SCM, and somehow managed to avoid HIV.</p> <p>UNETHICAL TREATMENT OF HAEMOPHILIAC CHILDREN - What happened to haemophiliac children was unethical. The lack of acknowledgement of haemophiliacs is causing great anxiety in our community. Those that escaped HIV are grouped together with whole blood victims, despite their experiences being vastly different. Dealing with severe haemophilia in the 70's and 80's was challenging. Before home treatment became available there were countless trips to the hospital, often in the middle of the night. Pain is managed better these days and joints have benefitted a great deal from prophylaxis, but in the 70s and 80s excruciating pain, was part of</p>

everyday life. As a teenager on home treatment (I treated on demand, not prophylaxis), I remember worrying about AIDS every time I injected myself. We knew factor was not safe, but the people we trusted with our lives were telling us it was. Finding out decades later that those people had lied to us, has been one of the hardest things to come to terms with. In the 80's, AIDS meant death, so at the height of the AIDS concerns, I refused Factor altogether. I insisted on cryo instead. My centre only agreed to this on the condition that I visited hospital for every treatment I needed.

They were punishing me for challenging them. I was not doing as I was told. There was absolutely no reason to deny me cryo for home treatment. Yes, it was a little more complicated than factor to administer, but perfectly manageable. When I was little, we even used to take cryo on camping trips, injecting by torchlight! I think it was this 'year out', free of Factor, that saved me from HIV. It causes me great anger that thousands of lives could so easily have been saved if we'd all been kept on cryo. Those that decided we should be told Factor was 'perfectly safe' should be named.

We've had the biggest and longest and most damning Inquiry in history, yet we've not named the perpetrators.

When you realise your own government does not value the lives of haemophiliacs, it changes your entire perception of mankind.

What happened to haemophiliacs was unethical, but the regulations decide whether this is acknowledged or not. This in itself, is unethical. The behaviour of our clinicians was unethical for sure, but haemophiliacs were the victims of unethical government. Every single one of us. The evidence has shown.....

We were knowingly poisoned. This is unethical. We were lied to. This is unethical. Our concerns were dismissed. This is unethical. Our youth was stolen from us. This is unethical.

Our education was compromised (and future careers destroyed). And it could all have been avoided. All of this is unethical.

Why were the lives of haemophiliacs valued so low? How is it that our government and our doctors felt totally justified in lying to our faces? I need answers to these questions in order to move on. I want to know who the decision makers were that played with our lives from behind closed doors. They committed crimes, why should they go unpunished? I don't want to see them locked up, living with their guilt should hopefully have been punishment enough. But I do want it on record that haemophiliacs were lied to. Denying this is denying everything that happened. Every haemophiliac in the 70's and 80's was a victim of unethical behaviour. The unethical award should be given to all haemophiliacs without question. Making out that some of us were wronged while others were not, is something the haemophilia community will never accept. We were wronged and this government can wipe the slate clean. Unfortunately, financial compensation is the only recognition of unethical practice we can hope for. The tariff that deals with unethical practice is minuscule, but even if it was only £100, it would still be recognition of the unethical practices that ALL haemophiliacs were subjected to. This alone, will perhaps bring some kind of relief to the burden and anguish we have carried with us for the last 4 or 5 decades. This is not a large financial award, but that doesn't matter because this is where the principle lies for haemophiliacs. Acknowledgement is closure. Everyone given infected blood is a victim, but how can it be even remotely fair to consider haemophiliacs were wronged in the same way as for example, someone that received a one-off lifesaving blood transfusion at say 30 years of age? There are tens of thousands of whole blood victims, but only about five thousand haemophilia victims. We are not the same.

Surely listening to someone who understands haemophilia and someone who understands hepatitis is the only way to make a fair judgement here. Has anybody in the cabinet office or IBCA ever done that?

I think a basic financial compensation for the 0-16 years (perhaps 50% of the annual 16+ years amount) from the age of infection, and also some kind of token unethical award, a nod of acknowledgement.

This could make all the difference to the discontent among haemophiliacs currently. This need not slow the claim process.

INTERFERON and FINANCIAL LOSS

This is a long one, sorry! But understanding why non-HIV haemophiliacs are so disgruntled with the tariffs requires further understanding of life with haemophilia...and particularly haemophilia with hepatitis on top. We may have somehow, escaped HIV, but our entire lives have been drained by infected blood, on top of our haemophilia issues. Haemophiliacs led the way to the IBI, yet 8 years later people still don't understand haemophilia. Severe haemophilia made employment difficult in the 70's and 80's. Before prophylaxis the type of career haemophiliacs tended to pursue would be those without risk of injury. I studied hard for a career that I found challenging and rewarding. I explained away my damaged joints and the obvious limp with 'it's just a bit of arthritis'. I made excuses for the regular hospital appointments with elaborate lies. I had dental issues, migraines, or someone else was ill. Anything, but tell them I had haemophilia. I knew that would be career suicide. Ten years into my career, I'd won awards, travelled the world and was earning a £75,000 salary (not a bad sum in the 90's). I was on track to do well. I'd lived my life with a determination that haemophilia would not get in my way, and I was winning. But I could not win with hepatitis on top of haemophilia.

Diagnosis was not an overnight moment in my life, so I don't understand how date of diagnosis is even a consideration in the regulations. I don't know how many years passed between being diagnosed and being told I was diagnosed with HCV. Even after being told, it took me several years to understand the impact hepatitis had already had and was yet to have on my life. How can I consider myself diagnosed? I certainly didn't know what HCV meant 25 years ago, but more importantly, doctors today still don't know the full impact of HCV and won't for a few more decades.

Diagnosis is still happening. When I was told I had hepatitis C, I was told in a matter-of-fact way, I had no reason to think C was any worse than A. I knew B was 'the bad one', but nothing more. They told me there was no evidence HCV could be transmitted sexually, so again, I think 'ok, it's not the bad one'. What they didn't tell me then, was that years later, Interferon would lead to anti-depressants, that lead to no longer desiring anything, no looking forward to anything and no ability to plan anything. They told me I'd probably been infected with HCV in the 70's. 'Oh well, I've lived with it for 30 years, if it was going to kill me, it would have done by now.'

But then there was talk of hepatology clinics, new treatments becoming available, the mention of a biopsy. 'Trans-jugular' was something I needed to Google.

'Maybe this is more serious than I thought.'

I had a wife and a baby. I had a great career; I was heading for directorship and whatever followed that. My own business? Being bought out? Retiring early?

I also had a mortgage the size of a house.

When I started Interferon (it was the early trial of non-pegylated), it was brutal. I'd never known anything like it. I fell apart that day and have never recovered.

I had no appetite; I was skin and bones within weeks of starting treatment.

Every day was a flu day. Maybe one day a week I felt barely ok. I was so weak.

Family life changed overnight. I would rant at the top of my voice over the slightest issues; my baby daughter would look at me with fear in her eyes. Other days, I would sob uncontrollably. The hairs on my legs and upper body fell out and have never grown back and aches and pains that started then are still with me 25 years later. I had lesions on my skin, went to the GP and was told 'if you want spots, you'll get them' I was sent for a chest x-ray and told by the radiologist I shouldn't be having an x-ray for 'tiredness' My teeth were aching (all of them!). I went to a hospital dental clinic and the dental team arrived in hazmat suits and called my name in front of a packed waiting room.

I've lost count of the 'oscopies' I've had. And the X-rays, ultrasounds, Fibroscans, MRI's, CT's and surgeries, but I still remember the trans-jugular biopsy vividly. No GP understood HVC and certainly no GP understood (nor understands) haemophilia with hepatitis on top! They didn't then and they don't now. It's too big a picture to take in, nobody has the time. I've needed hundreds of GP appointments over the years. Nobody is knowledgeable enough to put all the puzzle pieces together. They treat every issue as a solitary issue, instead of looking at the bigger picture. There truly is nowhere for us victims to turn. The

feeling that something's been missed, that I'm about to get an out of the blue terminal diagnosis, is something I live with daily.

At home, during Interferon, I didn't want to do anything, I was mostly in a trance like state. My wife had become a single mum of two, she was doing everything for our daughter, and everything for me. Only today can I see how much family life was stolen from us by Interferon. I have no idea how my wife has had the strength to stand by my side. To this day, she makes up for what I lack as a husband and as a parent. My mind played tricks on me. I needed psychological support but refused it. I'm a 60's child, we didn't do namby-pamby things like talk about our feelings. How wrong I was. Anyway, psychological support is almost impossible to get. Thoughts of harming myself, feeling that 'they'd be better off without me', have consumed me at times. I've been on and off anti-depressants for nearly 20 years. Nobody understands my world and I can't talk to anyone about it. After all, I live a lie. Go outside, put on a big smile and pretend nothing's wrong. I've had nightmares my entire life. As a young boy they were about being found out. I wanted to be the same as every other child, and the good thing is haemophilia is pretty much invisible to the outsider. But schools would make announcements in assembly's, 'beware of this boy (300 faces turn to look at me), you might hurt him'.

These humiliations have haunted me for decades. They turned me into a professional liar. I could blag my way out of every injury, every time I had time off school, blame it on anything but haemophilia. I just wanted to be normal.

Those childhood beliefs, I carry as an adult. Haemophiliacs that choose to hide their issues, in the hope of being treated 'normally' carry a huge weight in life. We have to live two life's. Interferon gave me new nightmares, and emotions are much harder to hide than pain. The people I trusted had lied to me My government wanted me dead The blood of prisoners and rapist has coursed through my veins I can't keep all this hidden any more

Oh, and something else playing on my mind forever has been that little thing called vCJD that I'm told I've been exposed to. I'm told it's nothing to worry about. So why then, do I have 'PUBLIC HEALTH RISK' plastered all over my notes and why must I tell anyone, before any clinical procedure, that I've been exposed to mad cow disease? Can you imagine how humiliating that is? 'Oh, and I've got Hepatitis C as well...but I'm not a drug addict, nor do I provide sex for money'. When I lose track of what I'm saying, go blank and unable to continue, as I often do, what do I blame, HCV, HBV or the early signs of mad cow disease?

My priority was always the mortgage. We must not become homeless. So, every day on interferon, I dragged myself out of bed and commuted to work. I had to, I had a wife, now two babies, and a mortgage.

Twice I collapsed on the London Underground from exhaustion. Please remember, everything above is thanks to Hepatitis and Interferon.

Haemophiliacs also had to deal with haemophilia.

The joint issues, the regular clinic appointments, the surgeries, the treatment trials, the fear that every time I had to stick a needle into my own veins, I could be injecting a new virus that hadn't yet been discovered.

(I think 8 years after 'clearing' I am actually beginning to see some improvement. My moods are less volatile, and I no longer cry watching Saving Lives at Sea.) But Interferon didn't work, I was taken off treatment due to a severe side effect and a few days later was my wedding day. I won't go into how hepatitis ruined that. Ok, no more toxins being injected into me. Honeymoon over, I'm feeling clean of drugs and getting my strength back. I returned to work and was promptly made redundant.

My consultant had written to my employer, to explain the treatment I was on and how it might affect me at work. They didn't even know I was haemophiliac, let alone had HCV. I was gone within weeks. A career ruined overnight. And how could I fight for unfair dismissal? My life was a secret. Haemophilia didn't destroy my career. HBV didn't destroy my career. HCV treatment destroyed my career.

The treatment for HCV ruined my career (among so many other things). To say anyone infected as a child cannot qualify for the supplementary financial loss award defeats the

very object of that award being established in the first place. This one regulation pretty much wipes out the entire haemophilia cohort from any chance of claiming. We were infected on and experimented on as children; it's no wonder you think none of us would be able to start a career. But some did manage, against all the odds, only for those infections and experiments to catch up with them later in life.

IBCA needs the power of discretion at times like this. The broader picture clearly tells a story that the regulations are not allowing to be heard. The Supplementary route for loss of earnings needs some discretion factored in.

The salary cap is set at a figure I was earning early on in my career, my true losses will never be reflected in any compensation, but to refuse me anything above the national average salary seems to go against the very fibre of fair compensation. It took years for me to get back into some kind of respectable income, my career had been put back a decade. But I was older now, less attractive to young companies and I was now too late to hope to ever run one. Eight years after failing Interferon I was employed again. Three years later, and after a second failed attempt with Interferon, I was not. The second round of Interferon took whatever I had left. Interferon had beaten me again. I fought back with what little strength I had, but after another redundancy from a freelance role, my career ended completely, 12 years before retirement was due. These are the wrongs not being recognised. The Supplementary route for loss of earnings needs some discretion factored in. This need not slow the claim process down.

WIDOWS

Hearing that widows will lose the 75% of support payments is very distressing.

But I think this is easily fixed. There is no point stopping support payments between a bereavement and payment of an estate compensation claim. We just need to reduce the time between bereavement and settling of estate claim. This is not complicated.

Interim support payments should not be deducted from final estate compensation. (It needn't be more than one or two at most.)

This will discourage unnecessary delays.

Gov should prepare now to process estate claim payments within weeks of bereavement; a guarantee of this kind would provide much needed reassurance to living infected blood victims.

People need to know, their people, are going to be ok. You've created a lot of concern and confusion, when you could have just said...

...after a bereavement, the partner will continue to receive 75% of support up until the point an estate claim has been processed. This should take no more than 4-6 weeks and interim payments will not be deducted from your final compensation.' There is no need for this to slow the claim process. SCM The SCM was awarded for a reason, SCM claims were submitted to EIBSS by medical experts. Dragging us through this all over again is nothing short of cruelty. We're exhausted and you're toying with us. Why are you punishing us? As it stands, to continue receiving the SCM element of monthly support payments, victims must opt for the IBSS route of ongoing monthly support. Those that need the lump sum now, are only allowed it on the condition they give up their SCM support.

How can this be? You're punishing SCM victims for choosing a lump sum. Uplift to cirrhosis seemed a reasonably fair way to handle the SCM issue, please be transparent and explain the thinking behind this harmful U-turn.

11 Then, please consider another option.

Allow victims that choose the lump sum to continue receiving the SCM element of their current support monthly as a monthly support. This would not cost the government any extra, so I struggle to see why it could not be an option. Surely, the non-SCM element of monthly support is considered when calculating the lump sum for SCM victims, in the same way it is for non-SCM victims?

That way, SCM victims will get the same core offer as non-SCM victims. The only difference is, SCM victims continue receiving their SCM element as monthly support, ongoing to HLE.

So, everyone has the option of lump sum, and SCM just carries on as it does now (no

	<p>different to if you were paying it to a SCM victim that chose the IBSS route). Two easy fixes. Neither need slow the claim process.</p> <p>THE AFFECTED Why is there no registration process in place already? A simple email questionnaire to the infected could get this ball rolling right away. Affected claims die with the affected. This is causing great concern among victims. Every affected victim alive on May 20th, 2024, should receive compensation.</p> <p>It's not hard to identify those that have passed since May 20th 2024, these people (or their estates) should receive compensation. They were alive when the IBI report was announced. The fact the government never got round to pay them, is the governments' fault. Not the victims. We understand the reason for the regulation that sates 'affected claims die with affected victims', but to follow this by announcing affected claims are likely to creep into the 2030's is inconsiderate. You could so easily make this complicated and very traumatic scenario payout a little less painfully.</p> <p>Instead, everyone is made to worry that they're going to die before they're invited to claim. Affected claims dying with affected victims means you are rewarding yourselves for tardiness. It's not difficult for names to be gathered and linked to the infected now, you have an opportunity to get way ahead of the game. But instead, you've made people fearful of dying and their compensation dying with them. Compensation too late for them, perhaps, but not too late for their families.</p> <p>My father asked me just days before he died in June 2024, whether compensation was 'sorted'. He didn't want it for him; he wanted it for his grandchildren. I lied to him. I believe anyone affected and alive on May 20th, 2024, should be considered for compensation. We are talking tens of people here, not hundreds, it won't require much effort. And you can always come back with a compromise.</p> <p>Perhaps estates of those that have passed, receive 75%.... of what was due to that affected victim. This would not slow down the process.</p> <p>Every haemophiliac treated with cryo or Factor in the 70's and 80's was exposed to HBV. HBV does not leave your body. Recognise co-infection for haemophiliacs treated in the 70' and 80's without the need for hospital records that are either missing or incomplete. You know factor was infected with HBV and we were being hit with it time and time again. Recognising co-infection in older haemophiliacs need not slow the claim process. Ongoing monitoring I'm not getting any kind of health monitoring. I managed to wrangle a Fibroscan through my GP, and the readings are higher now than they were when I 'cleared' hepatitis and was completely discharged by hepatology. My haemophilia consultant doesn't seem interested in this rising number and there is no talk of me seeing a hepatologist. I've got a list of things I need to see the GP about, they already think I am a hypochondriac I'm awaiting surgery I'm having therapy I have no work, and I feel worthless. The considerations I've expressed are costly, but they are not inappropriate. The 20th of May 2024 was a day to remember; we felt the end was in sight. Today, exactly one year later, and the end just seems to be getting further and further away. This government has the huge privilege of being empowered to put things right. Why not be the government that goes down in history as the one that ended more than half a century of torment for haemophiliacs. Please don't fall at this, relatively low last hurdle.</p>
5)	<p>I have read the proposal for prioritizing claimants, this to me seems like a way forward from the shambles of who gets the Golden Ticket on Tuesday. My Mum is an Estate claim with myself and my sister as affected. Mum is 76 years old and my major concern is she won't see the justice for my Dad GRO-A who passed in 1998, co infected with Hep B, Hep C and Hiv. The run up to his death was horrific, he got Fournier's Gangrene in his testicles and had open wounds,, skins grafts and HIV infected on his hospital room door. He was a 3 HR drive away and Mam was with him but ended up having a mental breakdown and needed to be sedated by the staff on the ward. I at the time had 3 Severe Haemophiliac sons and I could only visit on a Saturday or Sunday, that drive every weekend nearly broke me,!. What I want to see is those living and infected paid full compensation. But I also want widows who are registered with EIBSS to be settled,they are ageing and dieing. I would also like to see on the back of an Estate claim for all those family members to be processed and receive compensation as a whole family. Regarding IHT I think it's unforgivable for my Dad's Estate to be exempt at the first claim but not when it could be passed on to my Mam's beneficiaries this is wrong as Mam may not</p>

	live for 7 years after receiving my Dad's estate claim. I also don't approve that I as an affected daughter can not even register so I'm on their radar, how do they know who I'm linked too? How many affected children are known or numbers collated. Another issue is interest due on our claims, the first infected paid out are able to invest and gain interest, that's so wrong when you work it out, that is a lot of interest between first pay out in 2024 to when we as a family get to claim my Dad's Compensation.
6)	Yes, I agree with the proposals.
7)	<p>While I perfectly understand that IBCA is currently prioritizing claims of people who have 12 months to live, I truly believe that people who have died have paid the highest price of all and that their estates should therefore be prioritised. My father was co-infected HIV + Hep C, he suffered greatly physically and mentally due to the stigma, his last years of life were total hell, he died in 1989 at age 48, he was robbed of a normal and full life, leaving a widow and 2 children grieving him for 36 years.</p> <p>The following factors should be taken into account and the people from this group should be at the top of the list:</p> <ol style="list-style-type: none"> 1. Severity of injury – the deceased was co infected HIV + Hep C 2. Zero quality of life – no psychological help, no medical treatment - the deceased suffered greatly during his last years 3. Death sentence - the deceased suffered a violent death and his life was greatly shortened 4. Time factor - duration of grief - 36 years with no recognition nor proper compensation for the estates 5. Urgency - my mother is 82 and would like to be compensated while she is still alive <p>I hope this submission will be read and taken into consideration, and that this will have a positive impact for this group in the scheme.</p>
8)	<p>Haemophiliacs should be first in line not only because we have been infected the longest but also because we are suffering more side effects. This should also be further prioritised into age so older infected haemophiliacs should go first as they are most likely to suffer fatal side effects. There should also be the ability to further skip the process if an upcoming major operation or procedure is imminent which may be potentially fatal to assure they get their comp before the operation. There should not be a priority for dual infected or single infections. Whole blood should go next unless they are a priority in case of infection severity or advanced age or major operation that may be fatal. There should be the option to prioritise their comp based on need. Affected should go last I'm afraid as they aren't as in direct need of the comp. Again though the option to fast track in case of fatal illness or operation should the need arise. These are my thoughts on priority.</p>
9)	<p>Submission in response to Sir Brian Langstaff's proposal for a fairer scheme of prioritisation for compensation. I realise that this is a patch up of a ridiculously complicated scheme and that not everyone can receive compensation at once. If legal representatives were able to sort out the cases and supply the evidence there would be fewer delays, our solicitors know our cases well and have our evidence where it exists. I broadly agree with Sir Brian's suggestion, but what concerns me how this will work, it will require manpower to achieve, will that come from the Case Managers, or will the cases be prioritised by Legal Representatives, if the people are represented, if so surely payment for this service will be required. It may be that more staff will be required to continually update and re-prioritise the list, due to increasing age or ill health. This cannot be done by Case Managers as it will delay payments. I think that everyone connected to an infected person (dead or alive) should be called and processed at the same time by the same case manager. Especially given the drive to find new patients, new applications should be fully worked up, ie route of transmission, evidence required prior to being added to the list. Supplementary claims should be dealt with once all the first claims are finished</p>
10)	<p>My immediate feeling is that too many changes of this type will just introduce more complications and additional workload for the IBCA, who, as we unfortunately know, are already struggling to process compensation payments in an effective and timely way. The level of detail that may be introduced, over and above current prioritisation (All registered infected</p>

	<p>individuals, with additional priority given to those who, sadly, may be nearing an end of life scenario), seems wholly unnecessary and I doubt will achieve too much. Surely we need to keep this process straightforward and as simple as possible, which these suggestions will not do and some of which do not seem to make much sense; i.e. Why would those who have had Interferon (and potentially cleared the Hep 'C' virus) have a greater claim than those who haven't. If ultimately, the consensus is that these changes are desirable then I don't believe they should go further than Priority given to those Infected and on EIBSS scheme (these will be the most easy to locate and process, with much of the information already available) with additional priority given to:</p> <ol style="list-style-type: none"> 1. Those with potentially less than 12 months to live. 2. Those with advanced Liver disease or AIDS (clearly these people are at most risk of potentially shortened life expectancy) 3. Date of infection and current age - both of which will also have an impact on life expectancy. <p>Anything over and above this would just further complicate things.</p>
11	<p>i am 77 years old and as many more like me are getting nearer to the end of their lives, the point that i'm trying to make is surely in most cases claimants under 65 will have more chance of living longer than claimants over 75 i think this is a fair proposal.</p>
12	<p>I write as a core participant in the Inquiry, and also on behalf of my mother, sister and brother who have all submitted statements as evidence for the Inquiry. For context, my father was a Haemophiliac who was co-infected with HIV, Hepatitis C and Hepatitis B and died of AIDS in 1995 aged 52. We are fully supportive of the proposal for the scheme of prioritisation outlined and sent out by the Inquiry on Tuesday 13th May for the following reasons which impact our situation directly:</p> <ol style="list-style-type: none"> 1. My mother, widow of my late father, is now aged 81. Clearly, time is not on our side, therefore the proposal to prioritise estate payments to those over 70 (after those who have been told they have less than 12 months to live) is welcome it seems entirely appropriate that those oldest should be compensated before those younger. 2. The proposal to prioritise payments to those affected who are over 70 is also welcome, particularly as my mother's claim would 'die' if she were to sadly pass away before receiving the compensation due to her as an affected person. The dates being banded about by the IBCA such as 2029 before all affected are compensated, makes this proposal all the more important to us. 3. We strongly approve of the proposal that when an applicant, such as our mother, has a claim through both an estate and also as an affected person in their own right, both claims would be dealt with together. This would have the double benefit of speeding up the process, whilst also avoiding the bureaucratic and emotional toll of having to go through the claims process twice. 4. In terms of commanding trust, it goes without saying that this proposed scheme of prioritisation, being entirely transparent and logical, is much preferable to the current random and arbitrary IBCS process. As has been repeated many times, the current system appears designed to pay victims as slowly as possible, thus reducing the bill for the government. After all these years, and everything contained in the Inquiry report of May 2024, the Infected blood community deserve better, and this proposal, if recommended, would be a huge step in that direction. <p>We appreciate that this is simply a proposal for a prioritisation scheme and may not form part of the Inquiry's recommendations but we are fully supportive of it for the reasons outlined above.</p>
13	<p>Hi I'm an infected person with hepatitis C severe pains down my right hand side. I've been refused scans time after time. I'm constantly tired. Why are so traumatised with finding doctors notes examination reports? I have submitted all that I can to Colin solicitors I feel like I am at the end of my tether with my mental health and my health in general. I am tired every single day of the week and I need this sorting. Please consider me a top priority, thanks.</p>

14	<p>In response to Sir Brian's proposal for the order of payment of compensation: Question A(i) (ii) (iii) the answer to all three questions is yes.</p> <p>Question B interpreting this proposal to mean that all three cohorts of victims will be processed simultaneously and not in the order currently proposed by IBCA, if that interpretation is correct, then the answer to B is yes.</p> <p>C All core payments to all victims should be paid first, then loop back to pay the supplementary awards. It seems likely that the supplementary awards will take longest as more likely to be the subject of dispute. Whichever order of payment is applied, it would be better for everyone to get their core payments first so that the payments to the later groups are not delayed while supplementary claims are disputed.</p>
15	<p>I was of the impression that people already registered with a support scheme would be given preference in the unpalatable lottery of who gets invited to claim next. The reason being that these claims should be processed quicker due to the amount of information already to hand. This makes far more sense to me than trying to appease the headlines of people dying before they are invited. Surely the 54 old chronic Hep C example is in far more need for compensation to resurrect her life rather than the other poor souls who are nearer the end of their life. The whole system stinks and this is yet another waste of time, money and resources which will ultimately elongate the process even further.</p>
16	<p>Sadly my days of being able to understand the complex nature of these proposals. However, I do understand one thing. If I have to wait a year for my compensation to be in my bank I will have to repay over £35000. In addition I will have lost over £7,500 in interest. So, I will have lost of £42,000 through no fault of my own. Could you please let me know how that is fair or reasonable?</p>
17	<p>My understanding from the two day recent enquiry was to understand the delay in making payments from IBCA. It was made clear that they have now concluded the testing phase for core participants and that 100 persons would be invited per week which would be greatly increased once further claims managers are being recruited. It was also stated that all core participants which are registered with a support scheme would be invited by the end of 2025. It was also stated that claims once commenced can take between 6 days and 39 days until payment is made. I understand that all persons given less than 12 months to live would be asked to make themselves known, which seems fair. I strongly disagree with the potential proposal to further subdivide further groups in order to prioritise further as I feel this would prolong the process by utilising valuable resources away from completing claims. Whilst many are waiting to receive their compensation unfortunately there are no guarantees that any of us will live long enough to receive payment as there is no way of confirming live expectance. Everyone is important in this process and would like to see the conclusion of the process in order to get on with whatever time they have left of their lives. The purpose of the two-day hearing was to identify why the process is taking so long, keep the process as was clearly outlined by IBCA at the hearing, increase claims managers and ramp up the process of asking persons to submit their claim and make payment to them.</p>
18	<p>My proposal would be deal with end of life first then work your way down by age oldest to youngest.</p>
19	<p>This is challenging to write, but on behalf of my mother (widow), and our family, we feel time is limited as she is now 82 years old. We suggest that compensation for the relatives of the deceased should be expedited, particularly considering my mother's age of 82. Given the wording of '12 months or less to live' it is important to consider the uncertainties of health at this age. It would be logical to process my deceased father's compensation along with my mother's. Handling all out compensation together is practical since my mother is already registered.</p> <p>The other issue is IHT (inheritance tax). My mother, 82 years old, may not have many years left, raising concerns about fairness. Given her hardships and the government's longstanding refusal to acknowledge the miscarriage of justice, is it fair that she might never receive any compensation? If my mother receives the compensation from my father's estate and her own, she may not have many years to enjoy it without IHT, reducing the amount significantly. Our family, as next beneficiaries in both wills, would see a substantial portion reclaimed by the government through taxation. They gave contaminated blood to my father without his consent and he passed away. Now, the government offers compensation but wants to reclaim it through</p>

	<p>IHT. They should do the right thing and change this policy. My father had no choice and we haven't had a voice until now. It appears that the government sometimes overlooks the difficulties experienced by us and other victims. While some individuals may have free time, this is not the case for us and many others.</p>
20	<p>I agree that those who have less than 12months to live should be prioritized to receive there compensation but I don't agree that age over 60 or 70 should take priority as a lot under them age groups are not in good health being younger doesnt mean your healthier than an older person. whare infected deceased are concerned why are they not in the first group we was repeatedly told infected living and infected deceased will be treated the same and will be in the first group to be paid- repeatedly infected living and infected deceased will be treated the same- infected living or infected deceased-same and paid at same time so why have no infected deceased been included?why have you continued to lie about it?why do you go round tge houses to answer questions and not answer them at all? after everything do we all not deserve 100% truth and honesty? you are prioritizing those that have less than 12months to live and rightly so but what about the ones that have already paid the ultimate price- do they mean nothing? the infected deceased are one of the quickest and easiest ones to sort as you have all there info already,nothings changed for them as unfortunately they have no change in health so no upto date medical records needed so you got no excuses not to include them in the first group like you repeatedly said you would. I know there is no easy answer but old age isn't necessarily a priority.what ever you come up with for once please think before you say it and this time actually do what you say you will do unlike all living infected and infected deceased will be treated the same and paid at same time in the first group- lies - all lies and you wonder why no one has trust in you when you make it up as you go along and go round houses not answering questions especially when it's questions about what you have ready said about doing and as usual don't do it and ignore us-so much for open ,honest,transparent ,trustable - isnt it about time you actually did it. Thank you for reading this- I hope you do read these and not just file them as its just another way to make you look like your trying to listen to us and help us all but really you don't care and want to drag it out as long as possible so you all keep your high paid jobs as long as possible while we are still dying and suffering.</p>
21	<p>As someone directly affected by this tragedy, I wish to express my deep concern and frustration that, to date, neither I nor my two brothers have received any compensation or interim payment – despite our mother having died as far back as 1993. Our mother died as a result of this historic injustice, and yet her estate has not been recognised. Likewise, I have received no compensation in relation to my father’s estate who also died 6 days prior to my mother in 1993. Over three decades have now passed without any form of justice, acknowledgement, or support. This delay is not only distressing, but it further compounds the trauma that bereaved and affected families like mine have endured for years. We feel forgotten in a system that continues to overlook those whose losses occurred earliest. It is essential that estates – particularly those where the infected individual died decades ago – are given urgent priority. Many affected individuals who lost loved ones in the 1980s and 1990s are still waiting for the first sign of recognition. Our suffering is not less because it is historic – if anything, the prolonged lack of acknowledgement makes it more painful. The absence of interim compensation, or any form of financial or symbolic recognition, continues to feel like a denial of our loss. I support the Inquiry’s recognition that every claim matters, but this must include the estates of those long deceased and the individuals who remain affected by their loss. If prioritisation is to be applied fairly, historic estates and those still waiting for any form of compensation should be brought forward – not left behind yet again.</p> <p>In particular, I urge the Inquiry to consider:</p> <ol style="list-style-type: none"> 1. Prioritising estates where the infected person died prior to 2000, as a distinct category of urgency. The passage of time has been long and painful, and many affected families are now facing the loss of elderly next-of-kin beneficiaries without ever seeing justice served. 2. Giving additional weighting to applications from affected individuals who have received no interim compensation, whether personally or through an estate. These cases remain entirely unrecognised, and that silence is damaging in itself.

	<p>3. Acknowledging the emotional and psychological toll that ongoing uncertainty places on affected individuals – especially where siblings, like myself and my brothers, are united in grief and yet still fighting for recognition over 30 years later.</p> <p>The principles behind your proposal are sound – to minimise the number of people who die before receiving recognition, and to maximise fairness and transparency – but that must also extend to those who have waited the longest and remain invisible in the process. We do not ask for special treatment – only that the sacrifices and losses our family endured are finally acknowledged, with the urgency and respect they deserve. Thank you for the opportunity to make this submission. I hope the Inquiry will take these points into serious consideration and move swiftly toward a fair and compassionate resolution for all infected and affected individuals – past and present.</p>
22	<p>While I understand the logic and criteria being suggested I'm somewhat disappointed that it doesn't address the root cause issues - we need certainty and commitment on 'when', we also need to see the IBCA operating at pace and scale. If we (the infected) were given some form of commitment, such as 'within 12months' then I'd be more than comfortable with the proposal. However, if it remains open ended with no clear idea of 'when' I'm not sure how it helps me as an individual dealing with the uncertainty. The only certainty I'd have is that I'd now know that I'm towards the back of the queue, with no idea of when that queue ends. We need to focus on addressing the root cause - speeding up the IBCA's operating scale and processes. If we can't do that then I'd suggest that further substantial interim payments should be made.</p>
23	<p>I can see that some of the proposals are sensible, I don't agree with them all.</p> <p>While it seems a good idea to try and make the Cabinet Office and in turn the IBCA sit up and take notice of the latest proposals I very much doubt it will happen. My own circumstances are such that if anything happens to me, the amount payable to the estate of my late infected husband and my own affected compensation will die with me, I have no children as this was one of the many things we were denied because of the infections, how is this fair? Yes I understand people are passing away and should be prioritised because of this but as I said if anything happens to me the government would be rubbing their grubby hands together. My husband died and it feels like he, as well as the many other infected deceased do not matter anymore. Thank you for taking the time to read this, sorry if I come across as bitter, I'm just so depressed and angry that after fifty years we are still no where near finishing this absolute nightmare.</p>
24	<p>My father died in 1983 following his infection with Hepatitis C around 1975, following his treatment with factor 8, which resulted in his liver developing cirrhosis from which he died following an attempt by the NHS to carry out a liver operation; no payments of any kind were ever paid to my Father or Mother. I am the only child of my Father and I am now 72 years of age, so if I die any claim dies with me, which is quite possible considering the timescales for payments that have been suggested for estates by the IBCA. I managed to establish an estate for my Father around 4 years ago and I am now in the process of claiming an interim payment, which I hope to receive in the next few weeks, as I have been told the claim has been accepted. I do not feel it is acceptable to delay payments to estates; they should be a priority as many of the claimants will be like myself and might die before seeing any payment, and considering my Father died 42 years ago and has an established Estate, it is unfair not to make the claim a priority. I would like to suggest the following priorities are put in place regarding claims for estates and for claimants like myself, who are over 70 years of age.</p> <ol style="list-style-type: none"> 1) Established estates should be made a priority. 2) Claimants over 70 should be a priority. 3) An additional interim payment should be made to estates of a least £200,000. Immediately, to bring them in line with payments that have already been made to partners. 4) Claimants who have an Estate claim and an Affected claim should have both claims dealt with at the same time.

	<p>5) Legal support payments should be made available from the Solicitors of the claimants choice, as they will have supported the claimant to the point they are at now.</p> <p>The process at moment is not working in a fair and equitable way; it seems that barriers and procedures are more important than getting payments out to claimants who have established Estates and Probate in place. I feel my suggestions would go a long way to helping move things forward and recognise that Estates are a priority, as many of them go back many decades.</p>
25	<p>Thank you so much for reopening the Inquiry hearings and for inviting further feedback from core participants such as myself, an anonymous. Forty years on from my fiancé (later husband) being told he had HIV – and later that he had Hep C – , twenty five years since he died, two years since your compensation report and a year since your full IBI report, it is beyond belief that widows, widowers and partners still have no idea when the estates of infected deceased are going to start to be paid compensation. Nor do any of the living infected, in fact, left waiting every Tuesday to see if it is their turn that week. Chaos! I am fully in favour of the living registered infected being paid out first, but the existing Government/IBCA sketchy plan of the first affected victims starting to be paid by the end of the year, but maybe as late as 2029, even if the Paymaster General says this is only a backstop, is not acceptable. And there is no clarity that any such early payments for the affected will include estate compensation. It is listed third on a list after supplementary claims, but not specifically in this promise of first “invitations” by the end of the year. And we all hate these IBCA terns. But this is not just a plea for special treatment for estates, far from it. I am writing in a personal capacity but I am a steering group member for Tainted Blood. As such, I hear daily across the board particularly parents and siblings as well as partners who threw their lives into caring for the infected, lost them to HIV, Hep C, or both, or diseases arising from the treatment, and are now getting older and despairing of seeing justice. As you know, many have died and are continuing to die without seeing it, with claims dying with them. And the latter goes all more the so for the infected. We hear heartbreaking stories every day. And due to the continuing stigma or family pressure, many like myself are still afraid or unable to tell their stories more publicly. At the hearings, from those who feel able to speak out, you heard vividly how the delays over the past year have made matters worse, leading people to despair. One widow, aged 86, recently told me she had long campaigned but was now giving up and was just waiting to join her late husband. I am younger, in my mid sixties, but having recently had a younger brother stricken with cancer, wonder will I still be around in 2029? The Paymaster General, last week and this, acknowledged that the major problem is lack of speed in processing claims by the IBCA. He keeps saying he will do all he can to help, I hope that in your next report you can find ways of impelling him to do so. In particular their excuse has been “test and learn” and we heard at the hearing that they intend to use this when it comes to further groups. This horrifies me, as surely they have nothing left to learn. For estates in particular, the existing schemes and payment of interim payments to estates mean they have almost everything they need. Why more hoops and delays? There is of course every suspicion that the IBCA has been instructed by the Treasury to do a slow roll-out to save money, as people die waiting. And claims die with them for many. There are many serious faults in the compensation process we have been dealt, and I’m sure you are receiving a wide variety of suggestions for improvement. I will come back to the order of processing of claims, as a paper has been circulated on this, but to follow up on last week’s hearings in particular, there are a number of points I would like to highlight. The Paymaster General, Nick Thomas-Symonds, said that he would consider any changes which would not delay further any payments to victims. Surely, as for the most part any changes would be to increase level of payments, eg for hepatitis C victims generally or over the reconsideration he said he would give over the changes to SCM payments, these could easily be given retrospectively to anyone already paid out. Similarly there is an incredibly strong case for reviewing the level of compensation for unethical research and that too could be given retrospectively if it was raised. Amidst all the general gloom, it was good to hear that he might consider creating a supplementary route for the affected as well as the infected, so that partners, children, siblings and carers could apply for extra compensation where appropriate to recognise personal impact and loss, eg in respect of their careers. One thing that shocked me, and drew gasps from the audience, was to hear about a rejection letter of a claim where the HIV infection was prior to 1 January 1982, saying it fell outside the government’s liability</p>

	<p>window. Surely the emphasis has been on by first use of Factor 8 opening up patients to all kinds of viruses, and that the first infection date does not matter? I hope that you will be able to get this anomaly sorted out, or many who have used the compensation calendar and thought they were going to get one level of compensation may seriously lose out. Doctors knew early on that giving mass produced drugs from American blood donors would give Hepatitis and whatever virus might emerge next, and the Government was complicit in this. I was however pleased to see that in the paper the Government published yesterday updating Parliament on its action post your IBI report, on page 13 it says categorically: "The Scheme does not include hard cut-off dates or (I guess of) determining whether a person is eligible for compensation based on when the infection was acquired". As to the IBI's draft proposals for prioritisation of claims, I endorse all the good intentions behind this and agree there needs to be a more transparent way of starting claims than by what seems to be the present way of almost picking names out of the hat. I agreed with the present staging, starting with registered victims, and moving on from there, except for the fact that I believe that all supplementary claims should be moved to the end of the process as they will eat up the most time. What I feel is important is that everyone gets some more compensation as soon as possible, rather than everyone gets all they are due in one go. Having said that, to my mind and again to speed up the process for the maximum number of people, I do think that all those who are already registered with the previous support schemes should continue to be given priority, as the information is largely there, whilst still taking even wider account of anyone who has been given one year to live at the same time. I have a few provisos I would suggest below. I think that the registration of all who want to apply for compensation should begin immediately as a separate process. This would enable all those who have a year to live to be identified, of all groups and given priority alongside the infected. The infected list of priorities suggested I think works. After registration, it would take on board the Hep B victims who've never even had interim compensation. However I think the compensation for people deceased, should come next, before the people affected. Estate payouts will in the main benefit families and some of the affected could be benefitting from this. From the haemophiliac deceased estate viewpoint, where the maximum number of partners and others have waited the longest as the deceased died in the largest numbers many years ago, this would be just. I think the list of priorities proposed within this group is right. Then people affected should follow and the list works, I think.</p>
26	<p>We believe the Haemophiliacs were the first to be Infected and the worst Decades ago. They suffered the most and many as young children as was our beloved son, sadly now deceased. Therefore they should be given Priority, not only because of the pain, suffering and trauma [and not being told] but also the shame and stigma of the AIDS Campaign and the secrecy we were forced to adopt, resulting in much distress. Surely as the '1st Group' of Infected/Affected they could be completely dealt with and so out of the way for the next group?</p> <p>Bearing in mind how long ago the Haemophiliacs were given the Contaminated Blood, many as children [as our own son was] their suffering was immense as was that of parents and siblings. They witnessed the horrendous consequences of the scandal and ruined lives of all the families and the subsequent death of so many including our own beloved son. [GRO-A] was given HIV and Hep C in the early eighties. No matter what Government language 'they' wrap around it we still believe 'they' are unwilling to deal with the Compensation speedily for whatever reasons. How can we think otherwise or trust them after being so deceived and lied to in the first place by Doctors/Government and Politicians etc. Over and over again 'they' make us suffer more with their attitude as if we are undeserving and have no right to Compensation which seems to be given grudgingly. Over and over again we re-live the pain and stress and until this is settled and dealt with we can have no peace or closure. We and many others are nearing the end of our lives [83, 82] and fear we will never see the Justice so deserved and for those who have already paid the price of losing their lives never will. We live in a never ending nightmare with this process dragging on and on and we PLEAD this will be stopped by dealing NOW with what IS fair. Those Haemophiliacs Infected First and the Affected and so the longest sufferers, especially the children. Those who have already died without seeing any redress. Those Haemophiliacs still living but still suffering after decades. NOTHING can ever 'Compensate' for what we have all been through but Justice Must Be Done and Seen To Be Done. There have been too many 'WORDS' but we need ACTIONS [Not excuses]</p>

	that alone will prove Intent to recognise the pain, suffering, trauma and loss of life this absolute Scandal caused. Please note that I [82 yrs] am suffering the effects of Incurable Leukamia and the continued stress of this delay is adding to the detrimental effect on my health and wellbeing and that of my husband XXX 83 yrs.
27	<p>I would like to make the following submission to the inquiry regarding the prioritisation of claims to receive compensation. Firstly claims should be made to all people who have had a terminal diagnosis of twelve months or less. Then in my opinion it should be kept as uncomplicated as possible, to avoid further delays, and then approach people to make their application for compensation in descending age. I think it totally wrong that some people in their thirties and forties are having compensation offers before some of the Infected who are in their seventies and eighties. Reading through some of the examples given to prioritise claims is yet again complicating things to the extreme yet again, as in the formula devised by civil servants to work out a compensation claim, and would only cause further delays. I believe trying to work out who's illness is worse than anyone else's would be a impossible task, and again would cause delays. Just for once keep it simple and straightforward so everyone can understand it, People with a terminal diagnosis first followed by age in descending order.</p>
28	<p>I am a widow of an infected haemophiliac who contracted HCV from treatment at Treloars Was this email a joke?</p> <p>It seems absolutely farcical to be going over old ground such as this, rather than actually spending the time getting more invites out to people. I don't think there is any dispute that the living infected should be paid first, but these, frankly ridiculous and over complicated (particularly the last option) ideas seem designed to just hold everything up. Has anyone worked out how many people could be paid in the time it would take to sort out all the details and get an order put together, likewise, how many will die during this hold up?</p> <p>My thoughts are:</p> <ul style="list-style-type: none"> - Those on the IBSS schemes be done first . All our information should be there and we are proven as eligible. - If those that have less than 12 months left to live are paid first – will other payments carry on while these details are being gathered? Would paying the eldest first be quicker and catch a lot of the most ill. - How easy will it be for people to prove, or get proof that they have 12 months or less, without adding to the stress and pain this is already causing? - That the infected deceased are included with the living infected, as was originally planned, rather than pushing them further down the line as if they don't matter. - The core route is paid first to all. I understood that this was the original plan. Doing this would enable many people to get their full compensation, and those that want to go down the supplementary route do so after the core payments have been made, as it is likely that supplementary claims will take longer than core claims. This would meet the objective of the fewest number of people dying uncompensated. <p>Payments to affected-</p> <ul style="list-style-type: none"> - Again, proving having 12 months to live, could be traumatic and difficult. Personally, my health is not great, I have kidney disease which puts me at higher risk for brain aneurysms- I have 2 that are currently secured – I have been on dialysis and now transplanted. I could get another aneurysm and if it burst that would be it, game over. But no doctor is going to say I have less than 12 months to live. - Payments to eldest first would again seem the easiest way to do this. <p>I also think that things to be reviewed should include</p> <ul style="list-style-type: none"> - A tariff for death, or automatically getting the highest tariff. Our husbands and partners paid the ultimate price for their infection, many widows losing everything as they had given up jobs to care for their husbands <p>Comparable amounts for HCV as HIV. Payments could still carry on and if the amounts were increased any difference could be paid at a later date so as not to hold things up any more</p> <ul style="list-style-type: none"> - they were contracted the same way

	<ul style="list-style-type: none"> - there was no treatment when it was first discovered - When the treatment was used, it was absolutely horrendous and, in my husbands case caused many more health problems, which, with the hep C, led to his death. <p>I understand that setting something like this up is never going to please everyone, but this whole thing really does seem to have been a complete fiasco. If the IBCA were more transparent, and gave regular updates with figures, rather than just ' we invited more people to claim', and a proper timeline of expected payments rather than a vague date in the future, people may be more inclined to just wait their turn.</p>
29	<p>I feel that those either infected and living with HIV or estates where the infected have died from HIV should be prioritised. Nobody who lived through the AIDS panic of the 1980s and its necessity for those infected and affected to remain secret about it based on medical advice and media fear mongering, amidst a culture of judgment based on widespread cultural ignorance about the disease, will feel that comparison with Hepatitis infection is a balanced response regarding compensation prioritisation. Once the living HIV infected have been compensated, I think the estates of the dead from HIV infection should be then prioritised based on the year of death with the oldest being prioritised.</p> <p>Our dad died over 30 years ago. Our mum is now in her 80s, we still hold out hope that she will receive compensation for dads death before her own..</p> <p>An additional thought regarding acceleration of the compensation process, it seems quite sensible to me to group estates of deceased with the compensation of the affected at the same time using the same claim manager. Breaking the estate into a payment for the deceased and then later returning to individually go through each of the affected family members of the estate seems to be a less practical and far slower and more tortuous way of processing. Based on this method, the whole business would be concluded in one process in as short a time as possible, rather than dragging each member of the family through the process gradually individually over however many years based on a more complex process. I see no fair way to allocate priorities, someone is going to wait much longer than others. I do have an issue with the wait for compensation which I would like put to the Inquiry. If you have being paid £500000 as your compensation already/today, due to inflation running approx 3%, if your paid in a years time would be £15000 less in real terms. this will compound the further compensation is delayed. 1 year £15000, 2 years £30000, 3 years £45000 etc, and that is if inflation doesn't increase.</p> <p>I did ask the question to the IBCA, basically "tariffs are set and will not increase." full email included below.</p> <p>Good Morning (NAME),</p> <p>Thank you for contacting us. Firstly I would like to say how sorry I am to hear of how you have been impacted by infected blood products; we are aware that no amount of money can fix or justify the pain and hurt suffered through this experience. I would also like to reiterate that we're very aware that all those who are entitled to compensation have already waited too long, and our aim is to provide compensation as soon as possible. In regards to payments, as the tariffs are set the policy team has confirmed that as the regulations have been set in parliament we do not expect the tariffs to change. In practice, using the tariffs means that compensation will be calculated based on predetermined criteria and rates. To clarify, the tariffs set will remain, however, for those who choose to continue receiving monthly payments to their compensation package, these payments will be uplifted annually based on the September Consumer Price Index (CPI). I hope that I have been able to reassure you regarding this, however if there is anything else please don't hesitate to get in touch.</p>
30	<p>Firstly I will start by saying that I have already started my compensation claim and so the proposal doesn't directly effect me. I actually think that the current approach taken by the IBCA is by far the most pragmatic and fair way to deal with ordering claims. I am concerned that the proposal would add another layer to the process and rather than speed up the process would, in fact, add significant delays. The information that is being suggested could be used to develop an ordered list is not currently available to the IBCA. For the infected pretty much all they know is how much the IBSS is paying you and for the majority of the other groups they</p>

	<p>don't even know who the people are that need to be prioritised. I fully support the notion that those nearing end of life in any category should be bumped to the front of the queue, however beyond that I firmly believe that all living infected should be processed first. Indeed it is not possible to process most affected claims until the relevant infected claim has been agreed. During the inquiry and particularly post May 20th we have seen an influx of people wanting to make estates claims, often these people did not know the deceased infected, have only a distant relationship and have no lived experience of the infected blood scandal. Rather than using age of oldest estate beneficiary I wondered if it might be possible to prioritise on closest relationship to the deceased, so parents and children would move up the list but claims from siblings, nephew, nieces and the like would move down?</p>
31	<p>My proposal should be anyone over the age of 80 should be treated as a priority and in addition to that anyone over 80 with a health condition should be further prioritised. This should be to the infected and also the wife or husband of anyone that has passed away from being given the infected blood. Anyone that died in the 80's obviously had such a severe illness it took their life and the family should be compensated now as its already been almost 40 years waiting.</p>
32	<p>TRYING TO JUSTIFY REASONS TO BE MOVED TO THE FRONT OF THE QUEUE FOR COMPENSATION AHEAD OF THE INFECTED PEOPLE WHO HAVE HUGH RESTRICTIONS ON THEIR LIVES IS DIFFICULT TO PUT INTO WORDS, IT IS NOW 28 YEARS SINCE WE LOST OUR SON, 40 YEARS SINCE WE WERE INFORMED THAT HE HAD BEEN INFECTED WITH HIV DUE TO COLOSAL MISMANAGEMENT OF OUR HEALTH SYSTEM AND THE PROFESSIONAL INEPTITUDE AND STUPIDITY OF PROFIT ORIENTATED PEOPLE WHO SHOULD HAVE MADE BETTER COMMON-SENSE DECISIONS BUT WERE BLINDED BY GREED OR PERSONAL CAREER OPORTUNITIES. TO THE BEST OF MY KNOWLEDGE IN THIS COUNTRY NO ONE HAS BEEN CONVICTED TO WHAT AMOUNTS IN OUR EYES TO CORPORATE MANSLAUGHTER , AND EVEN IF THEY HAD 40 YRS AGO THEIR SENTANCE WOULD NOW BE OVER, WHEREAS OUR PAIN AS PARENTS PERSISTS MY HUSBAND REACHING HIS 83 BIRTHDAY IN 2 WKS TIME, AND I NOW HAVING REACHED MY 80TH, I FEEL THAT TIME IS BECOMING LIMITED TO GAIN ANY BENEFIT FROM ANY COMPENSATION UNLIKE THE PEOPLE RESPONSIBLE.</p> <p>The above statement is our feelings on this whole situation at this moment, and apart from the threat of prosecution to those who were responsible, I fear that the delaying tactics will simply continue.</p>
33	<p>A huge amount of time is being spent on trying to speed up a compensation process but instead would it not be possible to pay a sum immediately to all claimants already part of an accepted scheme for instance £600,000 and then carry out individual assessments for any further balance or payment. In that way everyone is guaranteed an interim payment straight away which will ease the exceptional strain on mental health and therefore diminishing life expectancy.</p>
34	<p>81 advanced liver disease with the consequences of it turning to Cancer.</p>
35	<p>I think the latest example of the IBCAs attempt to agree a formula for prioritising compensation claims is far too complicated, prioritises the wrong things - and risks missing the point of compensation. I hope you will be able to simplify the process in the way described below so that the recommendations of the Inquiry can be faithfully carried out. With thanks for everything you have done and continue to do for the victims and for justice.</p>
36	<p>My submission would be is that there is a fast track for people who have all the information required to proceed with their claim, if they publish the documents that are needed to proceed with a claim and you have them you should be able to claim straight away regardless if you are infected, an estate or affected which will speed up the process. The money that has been allocated by the government to pay compensation is available to claim so people who can claim now should be able to without having to wait.</p>
37	<p>I would like to make my submission on the undernoted grounds.</p> <ol style="list-style-type: none"> 1. Due to the failure of the I.B.C.A. system my anxiety and depression have become very bad. 2. I am 73 years of age and my mental health and health are starting to go down.

	<p>3. For the treatment of my hepatitis C I was on a disastrous two year course of Interferon and ribavirin which left me with not only with health problems but also severe depression. Both of which I never really recovered from.</p> <p>4. The longer this debacle from the I.B.C.A continues the more my anxieties and depression will deteriorate.</p>
38	<p>I am an affected person. I am speaking on behalf of my infected daughter. She has cerebral palsy has learning difficulties and is non verbal. She was infected in 1985 with HepC and diagnosed in 2018 by that time she had developed cirrhosis of the liver. She was a premature baby and was given "top ups" of blood from the day she was born until she left SCBU. My daughter is 40 years old and has been infected for 40 years. She has numerous health conditions on top of the infection and its consequences. She has severe cerebral palsy, she is quadriplegic has kyphoscoliosis, chronic type 2 respiratory failure, epilepsy and is peg fed. We have been told and have always been aware that she will not live to a healthy life expectancy. Although she has not been given a terminal diagnosis her health issues, it is recognised, could cause her death at any time. The proposed 'points system' made by the enquiry does not, in my opinion, take account of people who are in my daughter's situation. It seems to put age above length of time infected. It does not appear to take into consideration any other co-morbidities that people may be suffering from And there does not appear to be any category that covers her circumstances. I feel she is not alone but accept she is in a minority. This does not mean she should be overlooked (the first 16 years of her infection is already not recognised) and seen as a 40 year old with liver damage which would place her towards the bottom of the list and could see some affected people being paid before her! I as an affected person, whose life has been greatly impacted by my daughters infection, do not think or expect that I should be paid compensation before any infected person or deceased estate. I feel very strongly that these cohorts of people should remain a priority and stay at the top of the list to receive their compensation in full.</p>
39	<p>I meet some of these criteria, so could I ask your advice if it's worth me making a submission?</p> <ul style="list-style-type: none"> • I was infected with HepC in 1983. Undetected until mid 90's I think. • I have stage four liver fibrosis. • Brain fog and fatigue meant that I had to quit my job late 2023. They invited me to, but wouldn't document that it was due to health issues. I was a project manager on an £80K salary. I did get a severance payment of £20K. • I went through two 12 month courses of Interferon combination drug treatment which was incredibly punishing and I honestly don't think I've been the same since. They were also absolute Hell to go through. • I have constant abdominal pain in the liver area. • I have requested and received my GP records. • I have spoken to and requested my records from the Addenbrookes team, but that might another month before they arrive. • I have already provided all of the relevant info as far back as The Swinton Trust era, so have had the maximum payment from them, whenever that was. • I'm getting support payments from EIBSS. • I have developed oesophageal varices due to the fact that my liver is packing in. These are life threatening. As indeed is having stage four liver fibrosis. • I attend an ultrasound liver scan every six months and now have to attend for an annual gastroscopy. <p>While I recognise that you are not offering any individual advice, anything that you could offer would be most welcome. I'm concerned as I'm hearing that compensation for Hep C victims isn't that great. I'm not going to accept some figure that doesn't match my situation and would look to be seeking options if they ever get around to making me an offer. My health isn't going to come back now, is it, so I think all I have left now is the money. That's all they can do to ameliorate the situation.</p>
40	<p>I am the daughter of an infected person, who died as a result of receiving contaminated Factor viii treatment. My dad died in September 1985, so this year will be 40 years since he died. The</p>

	<p>sense of relief and justice I felt sitting in Westminster Methodist Hall last May did not last for long, despite the report delivery a wholly damning indictment on successive government and public bodies. I was pleased to see Sir Brian Langstaff re-opened the Inquiry for 2 days of hearings, focusing on the delays we as a community are experiencing in the compensation process. I myself, like many of the affected children are not on the radar of IBCA, as far as I am aware they have no idea just how many once children, and now like myself an adult, make up what we call "The Fatherless Generation". So, when they talk about opening claims to new cohorts and cite "backstop" dates I fail to understand just how they have idea of the volume of claimants. For me I don't trust IBCA, they are not the arm's length body the Inquiry called for, and sitting in the hearings this was confirmed when we heard how there was a duty to ensure public funds were spent correctly. The setting up of IBCA and the compensation scheme was done with no referral or guidance sought from with the community who have been affected by this, there is a lot of experience and knowledge within it, especially in campaign groups, but once again we were ignored and excluded. For me, they sought to blame the very legislation we had to fight to get through the House of Commons, in the form of the Victims and Prisoners Bill and the amendments contained within. These points were raised by Miss Richards K.C, that following the final report, despite the community repeatedly being told there was a requirement to wait for the final report, less than 48 hours after publication a compensation scheme was announced. This to me was a smack in the face and shows once again why there is an inherent distrust of Government. I would go so far as to say the whole community was gaslit, misled and lied to repeatedly and this is something which has happened over the years and continued despite everything. Then on top of the rather crass Linked In comment (now deleted) that I reported both IBCA and the Inquiry, which was raised with the IBCA witnesses. Sir Robert Francis seemed almost gleeful in telling us the team "rejoiced" when a payment went out. This comment is tone deaf. Paying someone who's been infected with HIV/Hep C or both is hardly a reason to celebrate, especially when these payments have been delayed so badly, and those who are getting paid are seen to be the lucky ones. Once again, they show out of touch they are. There was also a mention of a cut off date of 1st January 1982 for HIV Infections, meaning any infection contracted prior to this date is excluded for consideration, from the other attendees I spoke to there was consensus this was not something anyone was aware of, and the fact the minister agreed to "take this away" for further consideration further supported this is something which is under some doubt. Given my dad died in 1985 and we have no access to his medical records, how can we reasonably be expected to know when he was infected. We only know he was and that it was through his Factor viii treatments. I have concerns about the payment of compensation to people who rightly deserve it, but are in advancing years and deteriorating health, such as my mum. Her health has seriously deteriorated over the last 2 – 3 years, and I fear she may not live to see the compensation paid to my dad's estate, or to her as an affected person which is appalling taking into account what she personally suffered endured in the early 1980's while my dad's health was decimated following infection. If she should die before her claim is "accepted" by her, then any compensation due will die with her. How is this fair? Then we have on the flip side, should she see the compensation paid, if she dies we have to face Inheritance Tax, so either way it feels like the Government are either avoiding paying what's more than due, or clawing a huge chunk of this back due to delays we were not able to avoid. There is no way for us to begin a claim for her, as we must wait for the opening of her cohort and then her name to be pulled from a magic hat.</p> <p>Another issue is, from what was said there doesn't appear to be consideration of linking claims, so my dad's estate, mum's claim and then mine and my brothers as affected will all be processed separately. Surely it would make sense to handle these in one, with all documents being provided and reviewed once. This would then speed up the claim's process – maybe this is a common-sense approach. I am grateful to the Inquiry Team, Sir Brian and Miss Richards. Sir Brian has proved himself to be ally to this community, time and time again and I can never thank him enough for this.</p>
41	<p>I know this is a huge can of worms, however my husband and I believe that definitely people who don't have long to live should be at the front of the queue and that after that, people over 70 who are affected should be next, mainly because many people of that age are parents who have lost children (in our case in 1992) so we have already been waiting many years for justice and we are getting older. If we die before a settlement is made, it means that our daughter who</p>

	<p>was born after our son died would not get any justice and she deserves it, having grown up as an only child who has had to have counselling due to her problems with her brother's loss and her feelings that she was born as a replacement for our son. The other point we wanted to make is that people who have been registered with, and benefitted from the infected blood support organisations should be able to have their claims dealt with quicker than others. This would clear some of the backlog and also make the whole process appear not so daunting.</p>
42	<p>In my opinion, none of this is achievable. The IBCA won't communicate with legals. Legals don't know the current health situation of every client. Legals can't offer priority without current health situation of every client without medical information. Legals will not be reimbursed for extra time spent on each case addressing current medical status. The IBCA process would be slowed further by attempting this priority database route.</p> <p>Leaving holes for error. They would need to study each case in order to offer any system of priority. What happens when (not if) an affected family member is invited to claim prior to the actual living infected person is invited? Meaning, the infected position of priority affects the order of priority for affected invitation. Some infected are also affected, hep c hep B, interferon and ribavirin and have received interim. This is an absolute disaster in my case. 30 yrs of fighting and I get pushed to the back of the pecking order because of my age. I might suggest this order for ethical simplicity:</p> <p>End of life infected. Hiv & hcv and or hbv. Hcv (date invite predetermined in post 2025-2026). Hbv same. Estates of the passed.</p> <p>Personally, I prefer the current system.</p> <p>It offers hope. Any alternative would suggest and confirm further delay in my case and I assume, thousands of others in my situation. It's a very depressing outcome all round, order of current health is not an option with years ahead until invite, time is killing us.</p> <p>Blood inquiry / ibca needs to prevent delayed redress to the majority and not pander to the demands and dissatisfaction of an unhappy minority.</p> <p>The only orders of priority here should be the swift redress for at EOL.</p> <p>I also believe those who are infected and affected within the same familial group should be invited at the same time, offering closure on this horrific scandal for all in one family, not having to await a further invite 2 yrs down the line. We want this to end.</p>
43	<p>As you will be aware the majority of hemophiliacs were infected with HIV through contaminated blood products during the late 1970s through to the early 1980s and most of the parents of those infected are now elderly.</p> <p>My mother, for example, who lost her son to AIDS in 1990, will be ninety-five years old this September. As things currently stand, she will have to wait until 2029 just to have her claim for compensation examined. She may still be alive, but the odds are she will have passed away.</p> <p>She of course, is but one of many ageing parents, who are highly unlikely to receive any form of compensation for the loss of a son. There is an urgency here that will not be solved by 'moving people up the queue'. There needs to be an immediate payment made to ageing parents, like my mother, and this may be reasonably based on the details that Collin's Solicitors (and other law firms) have on record. To do anything otherwise will be to deny justice to the cohort of bereaved parents that are still alive.</p>
44	<p>This is to confirm that we are the daughters of someone who is now deceased, and that we ourselves are 76 and 77 old. How old will we be when we receive any interim payment let alone any form of compensation? Are they intentionally delaying this because it certainly feels like it to us.</p>
45	<p>I was infected with HEP C in 1982, I am now 83 years old with my wife 81 years old. We have had to fight for the past 43 years to get any form of recognition of this terrible disease and the compensation due to us, and are still fighting. I have known for a number of years that Hep C has severely damaged my liver which is a constant worry for the future. I have lived through the treatment of Interferon and Ribavirin which was terrible with lasting side effect that has changed our lives forever. Now we are having to live through the Tuesday lottery, to see if we are lucky enough to be selected to start our claim. the psychological effect on our mental</p>

	<p>health is just unbearable. I have no problem with the decision to treat the terminally ill first, but I not accept that someone of my age and medical condition should be part of the lottery, and would like to see that the over 80 years old should be treated as the next group selected. I am very concerned and angry that despite all we have been through since 1982 should anything happen to me my wife is immediately excluded from receiving any monthly support scheme payments, which we have come to rely on. I would have thought the least they could have done is to continue the monthly payment to her until her death or when she receives her final affected compensation payment.</p>
46	<p>I recently attended the 2 day inquiry in London. I agree the priority for compensation should be those who are living and infected. However, a number of issues gave me cause for concern during the inquiry regarding my Mum's case. In the absence of medical records the decision regarding compensation would resort then to a decision being made on the balance of probability. When I applied on my Mum's behalf to EIBSS her case was rejected on this basis. It was deemed that her death was probably caused by PBC which in itself is a rare condition. (Only 1:100,000 women get it - and it more often than not runs in families) We have never heard of this in our family and this decision was made despite my written evidence and also despite the fact that Hep. C is a much more common cause of Cirrhosis of the Liver. I sent a letter and evidence of research regarding these issues to EIBSS by recorded delivery in March this year. I have yet to receive a reply. I asked the EIBSS about the medical background and qualifications of those who made the decision - again - no reply that answered this question. In fact the last letter I received from EIBSS was written to me as though I was the infected person and not my Mum. I have little / no faith in a system that is meant to help and support victims both infected and affected by contaminated blood.</p>
47	<p>My views as follows</p> <p>This whole thing has become far too complicated which is resulting in massive delays which are going to go on for years. The prioritisation work lays an extra layer of complexity and delays and it needs to stop. I appreciate we are all different and we could all put in an individual claim explaining our circumstances and why we should get more than the next person - we will all be dead before they get to the end. They have provided an award calculator and while not jumping for joy I would take my offer as I just want it over - I am certain that I'm not the only one who feels like this . I think they should make us all an offer in line with the recommendations and let those of us who just want it over to take the offer and be paid immediately. This would clear a lot of people off the list and then those people who have the energy and the time to fight on for a bigger pay out to do that and I wish them well</p> <p>It's at least worth a try ?</p>
48	<p>I have provided a numbered list below of items I would like the Inquiry to take into consideration.</p> <ol style="list-style-type: none"> 1. IHT removed for estates. As it stands we will have to pay 40% of the compensation back as soon as the original beneficiary passes. This could be just a few days after compensation is received. This is quite frankly a grotesque move by the government. 2. Request that registered estates are brought in line with registered infected with an immediate second interim payment of £210,000 3. That affected claims do not die with the affected. 4. Elderly estate holders are seen as much as a priority as those with failing health. Priority must be given to widows and parents who are the aging affected community. I believe this is already in the proposal in some form. 5. Additional claim for the horrendous suffering caused by interferon. 6. Uplift for HCV so equal to HIV. 7. Pre-registration for affected. 8. An application form for those who can and have completed the compensation calculator(s) and have the necessary records/evidence in their possession. Their payment could

	be dealt with very quickly which would help IBCA's poor completion figures. A commercial organisation might call this "plucking low hanging fruit".
49	<p>Thanks for this.</p> <p>My views are that under no circumstance should the affected be prioritised over any living infected person. The prioritising (apart from those dying) should not come into it for living infected and should only be used for the affected after all living infected are dealt with. I feel strongly enough about this that if they don't do it this way I will seek legal advice.</p>
50	<p>"Should minimize the number of people who die before receiving recognition through compensation"</p> <p>Submission to the proposals on compensation from The Infected Blood Inquiry, core participant, (GRO-A) and family.</p> <p>A</p> <p>(i) We feel very strongly that as many people as possible should live to see their suffering recognized by the state. Our Dad, has never received a penny of compensation, and is nearing his 80s now.</p> <p>(ii) We agree that the number of a people who live long enough to see some benefit should be maximized</p> <p>(iii) We agree that the wait for people to receive ANY compensation should be minimized. We have waited 50 years already.</p> <p>B We believe that the proposal scheme as set out should achieve these outcomes, however, we know that any such proposals, unless accepted by government, are just words.</p> <p>C We cannot think of any alternatives to these proposals. It is urgent that people see their suffering recognized before they die. Like a lot of victims, Dad is becoming more frail and needs increasing help around the house. He worries constantly about the future, and this compounds the trauma he has already suffered.</p>
51	<p>The living with poor health and poor mental health also as my husband should be priority as his mental health is affecting our entire family either way everyone infected and affected need there compensation asap as no one should be suffering</p>
52	<p>Having been part of this process for many years, attending zoom calls, meetings, hearings including the last two days on the 7th and 8th of May last, it is imperative that the Inquiry must now listen and hear what those of us who are infected and affected have said. Up to this point, many of us feel that there is no real understanding, empathy or leeway to make the scheme accessible to those that need it the most. I cannot speak for others, although having spoken to so many over the years, I know the sentiments are the same. Everyone wants three things; CLOSURE, JUSTICE, and COMPENSATION.</p> <p>The following are my family's thoughts.</p> <ol style="list-style-type: none"> 1. The Inquiry must equally prioritise those who are both infected and affected and who have less than 12 months to live or who are over a certain age (70/80+). The Inquiry must consider this cohort of people, especially those affected/bereaved partners who will have suffered through their own or their loved ones' infections from the very beginning. These people would not have had the same help, financial or otherwise, or the same medical interventions that those who are still alive today would, and have, been able to access. Many have already sadly died or are in the midst of end of life care. Not paying compensation to this group of people as a priority will mean that end of life will come without them ever receiving the justice they have waited so long for. Not only would this be a travesty of justice, it would also be completely discriminatory against this entire group of people. 2. Thought should be given to those who have already been signed up with a scheme for many years. These people will have already gone through a lengthy and at times, arduous process of proving they are eligible to be part of the scheme and to receive some sort of monetary assistance. One of the key issues the community have with IBCA is the pace of payments, so focussing on these people must mean that more cases can be dealt with faster. The schemes, such as EIBSS, ran smoothly and efficiently. Surely, they must be the easiest cases to swiftly move through the system? Perhaps those that managed the now defunct

	<p>schemes, such as EIBSS, could be employed to work with and help IBCA with claims handling. They would be understanding of the scheme, the problems, and most importantly the need for expediency.</p> <p>3. Clarity and transparency must be given to where all cases sit within the process. Managing the expectations of those waiting to hear is unbearable. Having been given hope that the end was nigh at the Hearing in May 2024, the sluggish pace, the lottery style randomness of those being chosen and the never-ending excuses must come to an end. The bottom line is people want to know when they will be paid. For my family, extreme anxiety has set in with referrals to the NHS Mind Matters now in place.</p> <p>4. In Sir Brian's report, and as highlighted in his Speech in May 2024, those that had died (the Deceased Infected) were to be seen and dealt with in the same way as the living infected – there was no differentiation. Since that point, there has been absolutely no recognition of this cohort of people. They are merely referred to as 'Estates' which totally dehumanises these lost loved ones. As highlighted before, these people cannot be forgotten – they were the ones who suffered in all ways at the very beginning of this scandal.</p>
53	<p>I broadly support the form and intent of the Inquiry's proposal. However, in order for the process to operate fairly and efficiently, all cohorts must be processed simultaneously under their respective ranking schemes.</p> <p>There is no valid justification for why claims relating to deceased infected individuals were not tested alongside those for the living infected, particularly as they were originally included on an equal footing under the first set of regulations—rightly so. The testing of deceased claims must begin with immediate effect, not delayed by internal meetings and prolonged decision-making processes. The prior delay in implementing prioritisation for end-of-life claims—taking several months for a decision that should have been actioned in days—is a clear example of inefficiency that cannot be repeated.</p> <p>With the current number of claims managers available, there is no reason why a subset cannot be allocated to begin testing and roll out of other cohorts now.</p> <p>Additionally, unregistered infected claims should be allowed to register immediately—again, without excuse or delay. Following registration, these claims must also be tested without waiting for the completion of other cohorts. Dedicated teams of claims managers can be assigned to ensure this happens and rolled out concurrently with both living and deceased infected individuals.</p> <p>For affected claims, processing can follow directly after a related infected claim has been resolved, ensuring coherence without unnecessary delay.</p> <p>Finally, I must stress that the pace and scale of recruitment for claims managers is inadequate. The number of claims and urgency of need require this process to be ramped up significantly and immediately.</p> <p>In summary, the principle of fairness demands that:</p> <ol style="list-style-type: none"> 1. All cohorts are processed simultaneously. 2. Deceased infected and unregistered infected claims are not deprioritised. 3. Claim testing on other cohorts starts without bureaucratic delay. 4. Claims manager recruitment is accelerated to meet the scale of the task.
54	<p>the Enquiry, once again, showing how to obfuscate and delay a what should be a simple process into a ridiculous roller-coaster ride.</p>
55	<p>I only agree partly with the listing for people infected namely the following:-</p> <ol style="list-style-type: none"> 1/ Those with less than 12 months to live - agreed 2/ 80 or over - agreed 3/ advanced liver disease/liver transplant only (ie living with HIV I would not include) - so partly agreed 4/ The rest should be all together as currently and randomly selected. <p>Reasons being I see no difference between living with consequences of AIDS and living with consequences of Interferon treated Hep C.</p>

	<p>Equally someone 60 or over could live another 20 years so I see no reason for putting them higher up the list as will have ample opportunity to utilise the compensation.</p> <p>The same with those not having had interim compensation, as they will see compensation but maybe 12 months later and again will have ample opportunity to utilise it, so again see no reason why they should be a priority. I agree with affected except for the "age". If that means in age order ie older first then I disagree. Anyone under 60 should be done randomly and NOT in age order.</p>
56	<p>Sir Brian asked us to submit our thoughts or any revisions we would like to see in the compensation framework. I have the following points:</p> <ol style="list-style-type: none"> 1. Hepatitis victims who died before there were effective treatments should be treated the same as the AIDS cohort. To treat them differently is cruel and discriminatory 2. Children of the deceased infected should be able to apply for a supplementary award for additional harms caused to their lives 3. The arbitrary 1982 cut off date for HIV infection should be cast aside for those who were infected before that date 4. Given the estimated timeline of final compensation, estates that have already received the first interim, should be brought in line with other cohorts and be given a second interim payment 5. Deceased compensation amounts should be a par with that of the living. All who died paid the ultimate price.
57	<p>For applications by people infected is 70 or over is 60 or over For applications by people affected is 60 or over For applications to recognise the compensation for people deceased through estates Any beneficiary of the estate is 60 or over</p> <p>To give more support to estate claims my submissions are as follows The deceased infected person was coinfectd (ie had been infected with more than one virus) The deceased infected person had interferon treatment (with or without Ribavirin) The deceased infected person had advanced liver disease or a liver transplant. Thank you for taking time to read my request for submissions on proposal for prioritisation</p>
58	<p>He has been diagnosed with cancer and can't do the things that used to be able to do and it will get worse, said the thing cut out from him is melanoma, very aggressive, one of worst types can get so actually after cut piece out and all the rest, don't really want to go through again, avoids surgery if he can because of what happened to his son. He is of the view that his age, he is very nearly 80 and the fact he has been diagnosed with an aggressive form of cancer should be taken into account when looking at the priority of the deceased infected/estate claims otherwise might not live to see justice for his son. He got upset when talking about it all.</p>
59	<p>I hereby write regards the Inquiry inviting submissions on a proposal to help establish the most appropriate way of achieving a scheme of prioritisation which both is fair and commands the greatest trust as I wish to thank you for such opportunity given to me as one of the infected person within the community of the infected blood scandal.</p> <p>As I understood much of the evidence heard on 7 and 8 May concerned the speed of delivery of compensation and the Inquiry has also received a large body of evidence that the uncertainty of not knowing when someone can expect to receive compensation, and the random way in which people have been selected for consideration, are damaging in themselves in my opinion because am yet to be invited to start my claim applications which is very frustrating and concerning due to the slow nature of the scheme process to determine a claim. The idea of random selection of claimant is not the best way to determine this matter as I understood</p>

	<p>some people has been getting interim payment over the years and such people are still been invited to continue their claim if I may ask a question. What about other infected community like myself who has never been registered with any support body but registered with IBCA yet up to date I have not been invited to make any claim or paid any Interim victim payment as applied to my current position?.</p> <p>Sir I would like to plead with the inquiries to consider my case as a priority to invite me to start the claim process or receive the interim victim payment as a fair and equitable justified manner as applied to the infected communities in this categories in a way of accelerating this claim matter. The need to prioritise claims in an acceptable manner will be highly welcome in this process, which can be made simple for all to understand and possibly accept as being fair, transparent on which one claim will be determined with advance date duly communicated to the victim on when the claim process will start instead of random selection which put the infected victim in limbo and confusion, its rather very frustrating and complex regulations as applied to the compensation current processing at the IBCA authority. As the Inquiry is inviting submissions on a proposal to help establish the most appropriate way of achieving a scheme of prioritisation which both is fair and commands the greatest trust therefore I believe the above submission with be useful to this inquiries panel as clear, transparent, system for deciding which claims are to be assessed first and could be adopted by IBCA's instead of people random selections. I have not receive any invitation from IBCA to start the claim process this very frustrating and stressful for my wellbeing, after all this years of delays in waiting to process my claim, this is very concerning as my health continue to deteriorate every passing day due to my unending daily constant medication which is affecting my overall health both mentally and sociologically. It's a nightmare that have no ending insight as I trust the inquires will dispense and consider an equitable fair justice without further delays in this compensation matters. Finally I would like you to note I have not receive any interim payment or invited to start my claim which is compounding my frustrations and concern as I look forward to your timely resolving these concerns issue as above mentioned that is affecting the infected communities including myself.</p>
60	<p>I hereby write regards the Inquiry inviting submissions on a proposal to help establish the most appropriate way of achieving a scheme of prioritisation which both is fair and commands the greatest trust as I wish to thank you for such opportunity given to me as one of the infected person within the community of the infected blood scandal.</p> <p>As I understood much of the evidence heard on 7 and 8 May concerned the speed of delivery of compensation and the Inquiry has also received a large body of evidence that the uncertainty of not knowing when someone can expect to receive compensation, and the random way in which people have been selected for consideration, are damaging in themselves in my opinion because am yet to be invited to start my claim applications which is very frustrating and concerning due to the slow nature of the scheme process to determine a claim. The idea of random selection of claimant is not the best way to determine this matter as I understood some people has been getting interim payment over the years and such people are still been invited to continue their claim if I may ask a question. What about other infected community like myself who has never been registered with any support body but registered with IBCA yet up to date I have not been invited to make any claim or paid any Interim victim payment as applied to my current position?.</p> <p>Sir I would like to plead with the inquiries to consider my case as a priority to invite me to start the claim process or receive the interim victim payment as a fair and equitable justified manner as applied to the infected communities in this categories in a way of accelerating this claim matter. The need to prioritise claims in an acceptable manner will be highly welcome in this process, which can be made simple for all to understand and possibly accept as being fair, transparent on which one claim will be determined with advance date duly communicated to the victim on when the claim process will start instead of random selection which put the infected victim in limbo and confusion, its rather very frustrating and complex regulations as applied to the compensation current processing at the IBCA authority. As the Inquiry is inviting submissions on a proposal to help establish the most appropriate way of achieving a scheme of prioritisation which both is fair and commands the greatest trust therefore I believe the above submission with be useful to this inquiries panel as clear, transparent, system for deciding</p>

	<p>which claims are to be assessed first and could be adopted by IBCA's instead of people random selections.</p> <p>I have not receive any invitation from IBCA to start the claim process this very frustrating and stressful for my wellbeing, after all this years of delays in waiting to process my claim, this is very concerning as my health continue to deteriorate every passing day due to my unending daily constant medication which is affecting my overall health both mentally and sociologically. It's a nightmare that have no ending insight as I trust the inquires will dispense and consider an equitable fair justice without further delays in this compensation matters. Finally I would like you to note I have not receive any interim payment or invited to start my claim which is compounding my frustrations and concern as I look forward to your timely resolving these concerns issue as above mentioned that is affecting the infected communities including myself.</p>
61	<p>Urgent Appeal – IBCA Must Prioritize the Deteriorating Health and Mental Anguish of Elderly Victims Like My 89-Year-Old Mother</p> <p>Dear Infected Blood Compensation Authority,</p> <p>I write with urgency and heartbreak on behalf of my 89-year-old mother—a victim of the infected blood scandal whose final years are now overshadowed by unbearable suffering. In addition to the terrible side effects of the infection itself—which have deeply impacted her physical health over the years—my mother is now facing rapidly deteriorating health and emotional anguish. She suffers daily from excruciating pain in her knees, making even the most basic movement agonizing. Her mobility is nearly gone. Her independence is lost. But the toll is not only physical. Recently, she has just endured the devastating loss of three siblings. The grief has shattered her emotionally. Her mental health is in steep decline. She is quieter. Distant. Worn down by pain, sorrow, and decades without justice.</p> <p>This is not just about compensation—it is about dignity, acknowledgment, and basic humanity. Elderly victims like my mother cannot afford to wait any longer. Every day is a struggle. Every delay adds to her suffering. I implore the IBCA to prioritize my mother's case with the urgency and compassion it deserves. Please do not let her pass without knowing that her pain was seen and her story mattered.</p>
62	<p>Thank you for your email. My mum was the infected victim, now deceased.</p> <p>My issue with this is that IBCA barely seem able to manage with the criteria they have at the moment, let alone complicating matters further. At this rate, myself and my sister won't see our estate payment until 2028, and myself, my sister and brother won't see our affected payment until who-knows-when???? I am 56 years old, my sister is 66, my brother is 72. I probably have the worst overall health! The trouble with this is it pits all the victims against each other, divide and rule. We all have the same main goal but our cases are different. Everyone is now fighting for their compensation on their criteria, it feels like we are fighting each other to be considered for our 'golden ticket'. Essentially, if this compensation process had been started after the interim report, and had been set up truly independently with the monies ready to go, we wouldn't be in this mess. I would support end-of-life living victims as priority. My understanding was you couldn't make a claim as an affected until the infected's claim was sorted. Once you start bringing in age, or other health scenarios, it gets messy. You can be a fit and healthy 70 year old or a 50 year old with numerous health problems. Living infected with HIV/AIDS on good treatment may be living more independently than someone with chronic Hep C. Where do you draw the line? Keep it as it is, but start to bring in deceased infected estates claims who were registered with a scheme as they are likely to have a lot of information to hand and be relatively straightforward to process, therefore "quick wins" for IBCA. Don't complicate a system that is already struggling to cope with the very basics, as I think this will slow down and push back the timelines even more than they are already.</p>
63	<p>Application to Recognise the Compensation for people deceased through estates.</p> <p>In my case my son, I would like to see compensation for his lost life who paid the ultimate price especially at a young age. Suffered the Sigma in the 70's 80's and 90's no positive support from anyone when actually going through the dying process . On medical documents suffered from Hep B, Hep C, HIV leading to AIDS. No payment schemes in place , to support us through such a harrowing times, no one wanting to engage with us in theses times, we all know why. My wish would be for Ture Fairness The Infected Deceased to be treated equally being compensated in</p>

	<p>parallel with the the Living Infected . Also I would request the Infected Deceased families to be given the opportunity to be granted a Second Interim Payment as the Living Infected were. In my opinion the Infected Deceased are not being treated fairly equally from the start, as having no voice I wish for more equality for my son. It appears and feels to me personally as a parent the deceased boys treated badly. We are a small aging group and need more recognition for our boys in their our Right obviously I have not studied the Law but I feel the deceased treated badly their lives need to be respected sometimes I feel it depends who shouts the loudest and are able to attend Meetings in London with officials from IBCA or Cabinet Ministers. As a Affected Person all my pain sorrow grief past present and ongoing awaiting recognition , yes I agree when our application and Neil Dad being process this to run along parallel with GRO-A1 Claim. I am in my late 70's Dad being 82 years therefore common sense elderly parents time not on our side to remain on this earth</p>
64	<p>The proposed method of ranking of the infected, affected and those seeking compensation for peoples deceased seems appropriate.</p> <p>As many people as possible should live to receive compensation from the state, and those that are most medically vulnerable should be prioritised so that the benefits that they receive are maximised. It is clear compensation in these cases should also be expediated.</p> <p>I am 85 year old with kidney disease and have to undergo dialysis every other day, I would like to receive compensation for the loss of my only son, who died due to being infected with to HIV (and hepatitis B & C) from infected blood products received as a result of treatment for Haemophilia as a child. I would like my compensation expedited as an affected person, due to my age and chronic kidney disease, and also I would like my compensation expedited as the oldest beneficiary of the estate as well as being the executor of the estate of an infected person.</p> <p>Processing both claims simultaneously would be eminently sensible and provide some small amount of relief for the trauma and injustice of our loss, and the significant impact on our family. My wife (79) is also an affected person and her compensation should be considered under the proposed prioritisation scheme. I trust that this submission assists with the Enquiry and supports the need for the critical prioritisation of compensation under the scheme. If you require any further information please do not hesitate to contact me.</p>
65	<p>My brother died on June 9th 1985 due to treatment with contaminated blood (factor VIII). He was 36 years old. We have waited 40 years for justice, to have to wait another 4 years is unacceptable. I have also been diagnosed with multiple sclerosis which can shorten my lifespan. And also under the present ruling the claim can not be carried on to my son, age 38, and so dies with me. Justice will not be done. We have recieved nothing. I will be 70 next year (may 2026) 2. No interim compensation has been paid to this estate 3. personally I have not been paid interim compensation 4. 70 years of age with medical diagnosis (shortens life span).</p>
66	<p>Dear Sir Brian and the Inquiry Team, Thank you for the opportunity to contribute to your additional report to the delays in paying compensation. My and my family's concerns are the order of which the cohorts were determined, and the now reality of how they are being issued. This is causing delay for the 3000+ family's of the deceased infected (named as the Deceased Estates) On 21st May 2024, the IBCA proposal summary stated that deceased infected would be treated the same as living infected. In a statement from SRF, on 16th August 2024, on his recommendations to government, he said "Much of the compensation will be awarded in respect of people who have already died" We received an email from our solicitors on the 16/08/2024. This said that the government had accepted the majority of SRF recommendations. The IBCA scheme will be accepting applications in October, it will be initially restricted to those infected...LIVING AND DECEASED. In August 2024, Sir Robert Francis published his recommendations The first set of regulations to be laid in the Victims and Prisoners Bill, on 24/08/2024, stated that the regulations were to start paying compensation to the living infected and the deceased infected, registered with the IBSS or previous AHO groups, i.e, Macfarlane Trust, Eileen Trust, Caxton or Skipton Fund. It was stated that a 2nd set of regulations would follow to allow the IBCA to start to pay the affected and give way for</p>

Supplementary Route to start. On the 17th September the IBCA newsletter from SRF, the below was said Not all the regulations could be finalised in time for the Government's first deadline in August, and that's why regulations for those who have been infected were prioritised. This means that those who are infected and eligible, or where relevant their estate, will have their core applications for compensation considered first. Then on the 17th October, the stance changed. It was then written in the IBCA update that 'they can only process claims for infected until the 2nd set of regulations have been laid to start paying the affected'

Where in that statement does the deceased infected come in? On 8th January in the IBCA community update, it was letting us know about the calculator. The below was said Initially, the calculator will be for those who are infected or claiming for an ESTATE. We will develop the calculator further for those who are affected after the second set of regulations are laid in Parliament.

On the 10th February community update we were sent the below order that cohorts will be paid. At least we knew our deceased loved ones had a chance and were in their minds.

- Living infected people who are already registered with a support scheme. This is because we can already access their details through the existing support schemes, and know they are already eligible for compensation. We have already started making payments to this group and will increase the number of claims in this group through 2025.
- Supplementary claims. When the second regulations pass through Parliament we will - in law - be permitted to process these claims. People have told us that they want to settle their whole claim as quickly as possible, so when we have the new regulations in place we want to support people with this. We will need to work through and test how we will process supplementary claims, because the type of evidence people will need may be more complicated. But we'll aim to do this as soon as possible so that we can process both a core and supplementary claim at the same time.
- Registered estates. Those claiming on behalf of registered estates (where the estate has received an interim payment from a support scheme) have already met the eligibility requirements of their support schemes, so we can access and check this data. Paying one estate claim will often result in money reaching multiple people through the processing of a single claim, which could include both affected and infected people.
- People who are affected and linked to a registered infected person or registered estate. If an affected person dies before their claim is paid, then their own claim will not be paid to their estate. Community members told us it was important to make that clear. The eligibility of an affected person is determined by their relationship to an infected person. Therefore, if an infected person (or estate) is registered, then we know the affected people linked to that person are likely to be eligible for compensation.
- People who are infected but not registered with a support scheme (unregistered infected). This could include people who are eligible for IBCA compensation but are not currently able to claim from a support scheme. We know it may take longer to work through unregistered claims because eligibility hasn't been determined yet. It's likely these claims will be more complex.
- Personal representatives applying on behalf of an estate that is not registered with a support scheme and people who are affected and not linked to a registered claim. As with unregistered infected people, we know it may take longer to work through unregistered estate claims and eligibility will need to be determined. Why on earth would supplementary come before registered estates? Surely there is more than double the work load having to go further afield for information from HMRC etc.

This announcement made me cross, as we were told that the 1st regulations were to include the deceased infected and the 2nd set were to include supplementary route.

On 31st March the 2nd set of regulations came into force. The 2024 1st, and 2nd regulations were merged. As far as I am concerned, to hide their changes.

Somewhere along the way we received an update telling us that the bulk of INFECTED would be paid by end of 2027 and the bulk of AFFECTED would be paid by 2029. Again, where are the deceased infected in that announcement?

I attended the hearings on 7th and 8th of May. I thought we would hear something more positive from David Foley and Sir Robert Francis. I was absolutely flattened on their first session before the break when Jenni KC asked about the cohorts to be 'invited' There was no mention whatsoever about deceased infected. I felt the mood in the room changing as we all awaited to hear. A break was called, and I felt the need to ask Jenni about the deceased. Jenni said that they were included in the infected. I pointed out that this wasn't so, as no test cases have been announced. There seemed to be more Talking of the affected starting their claims before the end of 2025!

After the break, Jenni asked the question
'Is there any timescale when test and learn may start?'

David Foley

'There is NOT a timescale at the moment, we will tell people when we are ready to open the scheme up to them'

Jenni KC

'Will you be opening up and running them parallel?'

David Foley

'Some will have to go singularly, there maybe an opportunity to do some parallel '

WHAT KIND OF ANSWER IS THAT? There were we, all sat agasp. My world completely fell in. How can it be that every single announcement, in parliament or in the media quote 3000+ deaths, but yet not a single person deceased has had their claim started. Its unbelievable. Its like the Hokey Kokey...in out, in out of the mix, but, with our lives.

This to me is a serious delay, constantly changing their stance as far as the Deceased infected are concerned. I find it totally unacceptable to treat the 2nd biggest cohort in this way. As I have said before, many have never had any recompense since our loved ones died many years ago, and many have only just been accepted for the 100k interim payment (not without a fight) The schemes have never been in our favour, so we now feel it's time to compensate for the deaths of our loved ones as soon as possible

I full agree that the victims who have an end of life diagnosis should be paid first, but this in numbers should not affect the speed of paying estates. I said in my last email to the Inquiry on 12/05/25, that my 52 year old brother had been given a diagnosis of terminal cancer. Since then, he has had results for a scan. The cancer has spread to his spine. I asked his specialist nurse the question 'How long' Her answer was, 'Months, not years'

I tell you the above because when asked about people being near end of life, and being able to claim, David Foley or Sir Robert Francis said something on the lines of 'when that cohort opens for claims, we will ask the terminally ill to come forward first'

At the rate and changes that keep being thrown at the deceased infected, my brother will have died. He was not infected, he was affected. He was 8/9 years old when our beloved Dad was infected, he was a twin to our beautiful brother, XXX who took his own life after Dad died, due to lack of support from any network on how to deal with what Dad died of and how to cope.

I called the IBCA on 13th February to ask a couple of questions. I spoke to XXX, who seemed very nice. The call lasted 33 minutes. XXX explained he didn't know the answers but would call me back by the end of the week. I never received that call, and after all this time, I received an email yesterday, 20/05/2025 from XXX at the IBCA.

I have set out the answers to your queries below. How will the IBCA know who is terminally ill to help speed up their payments to these individuals, when they have already categorised the

	<p>cohorts for payment? You may have seen that for the currently registered living infected, we contacted them directly in April to ask that those nearing end of life come forward. This means that for those that may have been told that they have sadly 12 months or less to live will be prioritised and their claim will be supported first. We are committed to ensure that end of life is prioritised for all groups when the claim process is open to them.</p> <p>Why would they put the deceased infected estates after the supplementary route, the supplementary route for the living infected could take such a long time, due to having to produce further documents for proof of illnesses and lost wages. We were told that the deceased infected estates would be dealt with at the same time as living infected, to now be put 3rd on the list?</p> <p>There is no perfect decision for which groups can start their claim in which order. Our aim is to choose an approach that means we can start widening our service to more people as soon as possible. It is important to mention that we do not intend to finish one group before we start the next - there will be overlap and we have committed to start affected claims this year.</p> <p>Why can't they separate the claims managers into groups to deal with the different cohorts alongside of each other. They are not treating deceased infected the same as living infected, and aren't using our cases to build their service. We are the easiest cohorts, all information is readily available and won't change.</p> <p>With regards to your last question, I can confirm that any other past compensation awards received via litigation (e.g. those made by a court or tribunal or as part of an out-of-court settlement) will be deducted from compensation awards through the Scheme. Again, this points out that anyone with a terminal diagnosis will only be able to be priority when that particular cohort is invited. I now go to the 1982 cut off date that was brought up at the hearings. How can it be that after all the years that have passed and the HIV litigation in 1990, that our government, in the 2nd set of regulations, can decide to introduce a cut off date without any explanation for this? There was NO cut off date in the litigation, why are they allowed to introduce one now?) I find this absolutely appalling. My only explanation, and this is how I think now after dealing with the government's over the years, is that because they won't pay the Hepatitis C victims more compensation, they are finding ways to lower the amounts that HIV coinfecting should receive. This is horrendous. Our haemophiliac Dad's were given HIV by the State and the State should pay. THIS NEEDS TO BE ADDRESSED IMMEDIATELY I would like to finish by saying that me and my family thank you and your team for your outstanding work, and for keeping the inquiry open. We will await your report with the same, if not more anxiety.</p>
67	<p>I would like to know what provision is to be made for those infected individuals in receipt of compensation if their condition subsequently deteriorates will there award be subject to review hep c and progression of liver damage? Over the course of the last year or so, I have been diagnosed with chronic pancreatitis as an accidental finding following ultra sound scan for suspected hernia and wonder if there is any evidence data to establish this as a confidential extra-hepatic manifestation of Hep C and/or Interferon and Ribavirin. My situation is probably unusual in that as a front line clinician in a general practice and dental access I was subjected to a prolonged and sustained process or triple jeopardy by LHPCT/CHST, GDC and CQC in my opinion the consequence of clandestine panic over the perceived risk of transmission following my contemporaneous exposure to vCJD via a donated blood product which action was ultimately successful when medico legal insurer refused to insure me and impacted profound and lasting consequences on my finances health and well being countered only by my faith, hope , self belief, mindfulness and resilience. I have not been approached by any official body for a view to be involved with the inquiry despite my willingness to do so. I have never been in the ongoing care of specialist hepatology for regular review until the pancreatic issue was discovered. Following the webinar with Dani Holliday I requested a fibroscan via the local haemophilia clinic and was offered an appointment which has been moved to June due to unforeseen circumstances. I came across a document recently during my search for medical records which is ongoing indicating that I had a fibro scan several years ago which determined no fibrosis I forget the date of the scan but have the document I have never been offered CBT , despite being referred by my GP. During initial phonecall i was not judged to meet the steps 4</p>

change criteria. Consequential losses do not seem to have been addressed by IBCA and the Cabinet office but perhaps i am incorrect in that assumption. it is not beyond means to deal with each case on its merits and not subject to upper limit truncations. I have no idea what the prescribed upper limit is. The affected and infected have been side lined during the government and cabinet office decision making processes. There appears to have been a lack of candour, transparency and a lack of clarity in determining the rules of engagement for implementations by IBCA. I fail to understand why the legislative framework for the IBCA scheme was included in the victims and prisoners bill which took a considerable time to navigate the parliamentary processes as I recall it having been introduced for 1st reading on the 29th of March 2023 and did not receive royal assent until the 24th of May 2024 which was curiously the date of prorogation of Parliament and 2 days after sir Bryan Langstaff published ibi report under 22nd of May 2024 and even more curiously that was the same day on which Rushi sunak announced a general election to be held on 4th of July 2024. Parliament was dissolved on the 30th of May 2024 and reopened on the 9th of July 2024. The first set of regulations establishing the ibca were enforced in August 2024. It is surely not beyond the width of parliamentary ingenuity to create a more specific mechanism by which to address the infected blood regulation process comprehensively with consequence of the conscience transparency and speed it appeared to me that James quinault was clutching at straws and trying to justify delay and policy emanating from the cabinet office. The focus of financial reparation should be on those in greatest need irrespective of which they assigned to it appears that the proposed ibi plan is a good one the responsibility for the supply of infected blood products to the UK lies with the fda and pharmaceutical companies is any approach being made to these organisations in pursuits of acknowledgment of fault and reparation for those consequently disadvantaged by the infection caused by their contaminated products the delay in passing legislation is concerning as is the secrecy surrounding the deliberations of the cabinet office and their appointed expert committee of advisers. was it really necessary to encompass the issue of bad blood within victims and prisoners bill? To delay a scrutiny process by an early general election in 2024 and to follow a process which excluded consultation and discussion with legal representatives of the impact of hemophilia community and transfusion recipients and support groups following an inquiry which took 5 years to compete to the report stage and is ongoing government acted with indecency and recklessness and in setting of the compensation scheme accepting most of the report's recommendations but not all. the legal representatives of the ibi should have been integral to the process of setting up the scheme. Each of the infected effective and beneficiaries to the estates of the deceased groups could perhaps begin consultation on preparation simultaneously in order not to disadvantage any particular group.

Settlement to estates not involving affected survivors affected survivors could perhaps be dealt with after the living infected and affected cohorts. No claim should die with the deceased. Trusted expert clinicians involved with the inquiry must be assigned to the executive committee regulating the process. I fail to understand why the fda and pharmaceutical companies have not been indicted for medical negligence and there is a question of criminal accountability and vicarious liability. The approach of the government and cabinet office in regards to legislating the structure and practice of the ibca appears to be defensive adversarial, patronising and disrespectful to the integrity and worth of the victimised community. Each case is undue and each individuals circumstances must be taken into account and accommodated without impact and consequences, without perception and prejudice. Those in the greatest need should be engaged with first irrespective of the cohort they are assigned. Perhaps the FDA and pharmaceutical companies could be offered by the government, the opportunity to make amends by ex gratia payments to victims and support groups and uk tax payers whom it would seem are supporting the cost of the inquiry and reparation through no fault of their own. Perhaps i have missed something and action has already been suggested or taken by the IBI, cabinet office and the government in that regard. Actions and omissions have consequences whether intended or not and those with responsibility must be held to account. The consideration of the circumstances of each should be all encompassing and not restricted by banding limitations so flexibility and compromise are essential and must not be restricted by political dogma, prejudice and perception.

Further to your recent Inquiry hearings and subsequent request for suggestions for the compensation scheme I would like to make the following suggestions.

In addition I would like to add that once again yesterday I was not one of the lucky ones to receive the random invitation from IBCA to claim my compensation but again read of a couple of 40 year old mono infected HCV who have cleared the virus and still working have been invited, in my opinion it feels as though IBCA are discriminating against me due to HIV infection. It appears that IBCA are choosing the cheapest claimants first. IBCA have invited nearly 900 claimants but i know of only a handful of co-infected that have been selected so far and IBCA will not give a breakdown of cohorts invited which is not transparent therefore hiding their discrimination towards HIV.

Order of prioritisation

1. Co-infected victims living with HIV and HCV over retirement age (66 years)
2. Co-infected victims living with HIV and HCV below retirement age
3. Age 80 or over
4. AIDS and advanced liver disease
5. Advanced liver disease
6. Over retirement age (Age 66 years and over)
7. Age 60 years and over
8. Consequences of AIDS
9. Never had interim compensation
10. Had interferon treatment
11. Age

Co-infected victims should be prioritised before a general age group as this small group has lived with the knowledge and health impacts of their deadly viruses for over 40 years and the mental anguish that this has and still does cause is immeasurable. To live with the thought of dying for over 40 years is unfathomable for the vast majority of victims as some only found out about their mono HCV virus in 2020 or even later. There is still no known cure for HIV whereas mono HCV is curable.

A suggestion for co-infected victims is that they have their claims assessed and paid by their current support scheme as the majority of information will already be held by the IBSS and the calculation for a co-infected victim is very straight forward, this would achieve a speedy outcome for this group.

I have suggested that over retirement age, as an additional category, be compensated before over 60 as there will be some mono HCV victims who are still able to work at 60 years old whereas a retired victim does not have this available to them and will now be living on a pension.

A further suggestion would be that once the prioritisation has been decided then IBCA should place all victims into their relevant category and give all victims a date for their claim straight away as opposed to selecting victims on a weekly basis. This would then greatly alleviate the stress and anxiety caused by checking emails every Tuesday to see if you have been randomly selected as is the current IBCA system.

Also, as speed is of the essence, IBCA needs to employ and train claim handlers at a faster rate than is currently happening. The current support schemes employ staff that are fully trained and understand the needs of the victims so why not utilise some of these employees with their wealth of knowledge?

	<p>One final point, the current tariffs were decided in 2024 and have not been increased in line with CPI in April 2025 therefore this needs to be addressed urgently as lump sums are now worth less than they were in 2024 due to cost of living increases. Compensation should be increased in line with CPI each year to keep up with cost of living and to make it fair to the ones that have not yet been paid.</p>
69	<p>I have received some compensation, which is meant to be "interim", since when, not much has happened. I feel like this Inquiry will never end and the infected people are being strung along with empty promises. I was treated with interferon for years starting in 2005 after my infection of hepatitis C was luckily discovered in France. It took over my life but at least I'm still here. I think if I had still been living in England I would be dead and would never have met my grand children as luckily due to my excessive tiredness I was given blood tests in France that found the hepatitis. I was given an infected blood transfusion at the birth of my second child in 1982. I feel after years of being fobbed off about my symptoms with anti depression tablets by the GP at the time, which I still have to take, I've waited and suffered long enough. None of the infected people should have to wait a minute longer. I continue to have poor health and very little resistance to whatever bugs are going around. I am now living with my daughter and her family still in France. Who moved their life here to be closer to me. The treatment for the infection was very debilitating and I was very ill at the time and I feel my life was, and continues to be, destroyed by this dreadful mistake by the health service.</p>
70	<p>2. My husband was infected with the Hepatitis C Virus (HCV) from a transfusion of contaminated blood at the Wrexham Maelor Hospital (WMH) in 1981 or the RAF Hospital, Ely (Ely) in 1983. Without knowing it, he had been infected with HCV for almost 40 years, and this was only told to him in 2019. He died on the 21st of February 2021 of illnesses arising from HCV including liver cancer. He was told he was a carrier of Hep C (then non-Type A or Type B) in his early 20s and that he needed no treatment but should refrain from having any more children, and to inform any medical or dental professional and any sexual partner of his 'carrier' status. He carried shame about it as it was, he felt a 'dirty secret'. He was in the RAF and was told by a senior officer not to discuss it as people would judge him badly as the illness carried a stigma. By the time his liver failed in 2019 he already had end stage liver disease and advanced cirrhosis. He had developed hepatic cancer by the end of 2019 which was untreatable and multiple other complications. As 2020 was the year of COVID his last year required me alone to nurse him through his illness to death as MacMillan and GP support was only delivered remotely.</p> <p>3. This witness statement has been prepared with the benefit of access to my husband's full medical records. This Statement should be read in conjunction with my husband's Statement and my first statement.</p> <p>Section 2. The Proposals for Payment May 2025</p> <p>4. The proposals rightly prioritise the living affected, of who around 3500 are registered with existing schemes. In evidence from David Foley given to the inquiry on the 8th of May 2025, it was said small numbers, under 500 had been processed through the IBCA's claim assessment process. The longest time to process was quoted by Mr Foley as being 39 days. Plans were in place, supported by staffing level increase, he asserted, to deal with the whole of the living affected (a further 3000 to be processed) by the end of 2025. These cases would be, it would be reasonable to posit, less problematic with more evidence than those who have never been registered with any scheme.</p> <p>5. The proposal made by the inquiry in May, following the 2 days of evidence, attempts to level out and provide an equitable framework for handling the many thousands of yet unregistered 'living affected'. It also provides a list of potential criteria for handling estate claims based on age, potential terminal health conditions and previous interim payment status.</p>

In this selection process, and I deal here only with the estate claims, the proposal is currently inequitable and fails to consider the whole situation of the bereaved who are registered.

6. In my case, and I am aware, albeit from non verified testimony from others across social media and various condition specific groups affected, that almost all the registered bereaved are, at their youngest in their early 60s. I am in my mid 60s. They have, as have I, had years of looking after the infected, not understanding what illness was affecting him until, in our case in 2019 a death sentence was given. I worked to the end of 2019 in my own business (which was established in 2009) and was unable to work until approximately 12 months after my husband's death. During the time that I was unable to work the income from my business plummeted as did the goodwill as I was unable to work for my clients. This was at the same time that my husband could no longer work too. I had various medical issues of my own which were put on hold until after his death and my own health suffered from the 2 years 2 months of caring for him 24/7/365 and many times earlier when he was ill with the HCV being treated for flu and gout when it was a flare up of the HCV symptoms. I am not over 70 nor terminally ill, but under the terms of the proposal my late husband's death would not be acknowledged nor my financial situation helped for years. I received in 2022 a payment of £100K, this barely covered the financial costs and debts caused by his and my inability to work and the loss of income from 2 businesses. The impact was such that even when I was able to return to work my return was gradual and even to the date of this statement, I have been unable to build up my business to the income levels before my husband's 2019 death sentence. I, along with many others, instead of a retirement, have had to remortgage their homes (a difficult process in your 60s) and continue to work for many years to make ends meet. This is entirely due to the loss of the infected person and the debt burden loss of earnings create.

7. There is also a lot of stress and complete lack of closure in having to hold onto medical records, write statements, watch content relating to this issue and generally be involved until the IBCA handle my claim and the estate claim. It is unthinkable that this stress, this lack of and end date, or indeed any idea on how long it will take to handle and pay the estate claim, is going on 4 years after my husband's death and many of us are in the same situation. Moving forward after a death is healthy and expected, I am tied to the worst years of his life by the prolonging of this aspect of the horrible mess that is the contaminated blood scandal.

8. The fairest way to handle this would be to deal with the registered estates after the registered Living Affected in tandem with opening registration for those who are living affected but have not been able to claim. Those unregistered cases for the living affected are potentially problematic evidentially, with many records being destroyed. Their claims needing to be assessed on the balance of probabilities and the many appeals that will no doubt follow initial registration and assessment. These additional cases, of which there could be many thousands, should not be prioritised over the affected registered bereaved who have already proven their claim entitlement. The death of their infected person should not be disregarded, and we be placed at the back of the queue as our spouses died without even knowing of the existence of this compensation. We should be paid after the living affected registered and at the same time as registration of other wider living affected cohorts not made to wait indefinitely.

The fairest way to handle this would be to deal with the registered estates after the registered Living Affected in tandem with opening registration for those who are living affected but have not been able to claim. This is because

(a) The registered estates have already gone to great lengths to show their entitlement to compensation having met the requirements of the various schemes. For us, this included my late husband spending many hours during the period of time in which his life was coming to an end to achieve this. For example, many calls, letters and emails to search for and retrieve medical records. It would be inequitable to dismiss the great physical and emotional efforts he, and many other successful claimants like him, have made.

(b) Those unregistered cases are potentially problematic evidentially with many records being destroyed. Their claims need to be assessed on the balance of probabilities and the many

	<p>appeals that will no doubt follow initial registration and assessment. These additional cases, of which there will be many thousands, should not be prioritised over the affected registered bereaved who have already proven their claim entitlement.</p> <p>(c) If this process, which appears likely, is that the registered living affected are to be dealt with in 2025 and estates in 2026 then a further interim payment should be considered for all of us who are waiting. Whilst this would not be closure it would assist in making the wait for final closure less stressful. Coupled with this clear guidance should be issued on what is required for estate claims so this can be prepared. Many of the bereaved did not require probate and it is not clear as to whether this is needed for the estate applications or a will showing a sole beneficiary is sufficient. The lack of certainty over dates of payment and evidence needed is exhausting and stressful and comes so late after the death of loved ones, it's like a wound that does not close.</p> <p>(d) The lack of speed was well ventilated during the 2 days in May within the reopening of the inquiry however it is coupled with lack of transparency over future ability to handle all the cases and an overall feeling of an amateur ill-prepared organisation in charge of payments. Can the inquiry continue to investigate on a yearly basis until this shamble is concluded? The IBCA should be held accountable to more than Government on this issue and the demonstrations by groups involved.</p>
71	<p>I propose that the compensation should be top of the list for the boys who were infected at Treloars and their families. The boys and their families have suffered this horrific nightmare for over 40 years! Sir Brian Langstaff stated that the pupils were often regarded as objects for research and this was unethical and wrong!!!!!! These boys were living away from their loved ones and hidden away in sickbays at a school the parents believed the boys were in the safest hands, this was truly horrific! The boys were stripped of a healthy life before the age of 18 and their mental state was changed forever. The boys who are still alive are now in their late 50's and they have lived with HIV and viral hepatitis for too long, they need justice NOW. Their parents are over 75 yrs of age and also deserve this justice NOW. The boys who have tragically passed away deserve to be honoured with justice NOW! Some of their estate beneficiaries will be nearing 70 and they deserve justice NOW! These boys died in a way that was barbaric, they lived in fear and the suffering mentally and physically was torture to them and their loved ones. The boys were in very close contact after leaving Treloars and over the years they were learning that another of their closest friends had tragically passed away, this was not normal news to men in their 20's! Each death they learnt of was another heartwrenching blow to who is going to die next! As a sister of two deceased boys of Treloars, I have lived to watch my 2 beloved brothers go through total living hell and watched them both struggle through their short lives and then to die from the most brutal deaths, this will haunt us all forever!</p>
72	<p>Our mother is now 82. She is registered blind, has low mobility and is extremely vulnerable. She is currently receiving domiciliary care and is supported by her children/family. She currently presents with both chronic and acute anxiety and has suffered three significant mental health related episodes which can be directly attributed to the negligent and complicit actions which ultimately resulted in her husband's death and her continuing fight for justice in his name.</p> <p>We feel it extremely insulting that our mother has to be invited to make a claim, but as this is the terminology being applied under IBCAs compensation scheme, then we think it not only reasonable, but fully justifiable that the IBCA invite her to begin her claim process immediately. My mother sees no difference whatsoever in the current prioritisation of a living infected person over and above that of an affected bereaved partner (in our case a Scheme registered widow) as all relevant criteria would have already been fully assessed and met. We therefore, see no sense or reason for any unnecessary delays in the processing and resolution of her claim entitlements. Our mother has struggled significantly both emotionally, and financially for over forty two</p>

years, caring for her husband and having had to watch him die in utter sufferance from HIV/AIDS, aged just 42, following his illicit treatment with a contaminated product (FactorVIII). A treatment, which in fact, he did not require as a mild haemophiliac and especially as the significant risks associated with such treatment were already known. All of this, whilst also trying to bring up three young children and keep a roof over our heads.

It is not unreasonable, therefore, to insist that the IBCA considers and provides our mother with the necessary assistance to allow for the immediate processing and full payment of not only her personal claim, but also that of any other relevant claim entitlements she has in relation to her late husband's treatment and estate. This will not only help to bring her the peace of mind that the justice/compensation due to her has been fully considered but has also been fully resolved. Help her to get closure please, she deserves this and has had to wait for, for far too long for resolution. We can only hope that our mother has the opportunity to live the rest of her life, however long that maybe, free from the continued worry of financial burden, unresolved redress and the need for association with those who continue to create so much uncertainty and distress in her daily life. We implore you, IBCA, do what is right and just, please don't let her continue to suffer any longer than she has already and allow her the opportunity to live the remainder of her life free from further continued trauma and distress associated with this scandal. General comments for speeding up the process in the prioritisation of claims Dealing with cases for immediate family affected persons, (siblings, parents, bereaved partners)

could help families to start moving on with their lives knowing they have been recognised and have received some level of justice, albeit through financial redress. There should be no disparity or delays in the prioritisation and processing of full claim entitlements of registered, affected bereaved partners over the living infected or associated others. Sufferance, loss and timely redress cannot simply be assessed, measured and prioritised on the basis that someone is infected but still alive. Bereaved families continue to live in abject sufferance as much, if not more, in having lived with, cared for and watched their loved ones die as a result of their treatment. Case reviews must consider and reflect this when prioritising cases.

Using case by case criteria which are essentially the same or similar in context could serve as a learning tool to process claims more quickly.

All infected person or affected family claims should be prioritised and fully resolved where HIV/AIDS (and associated co-infections) resulted from treatment using contaminated blood products. The trauma and distress caused by keeping such an imposed family secret for so long continues will have a profound effect on emotional well-being and physical health. Some families continue to live with the fear, stigma and shame so commonly attributed to HIV/AIDS. Be under no illusion, people are still very ignorant at the mention of HIV/AIDS and the fear of gossip, having substantial financial awards and the potential for socially intolerant behaviours remains, especially in smaller communities. Prompt redress may help families to better manage or remove potential community related risks associated with intolerance, ignorant attitudes or jealousy (financial award). Developing and maintaining a secure and readily accessible register of all affected bereaved scheme registered persons (relevant IBSS) could aid in the prioritisation and processing of associated and relevant personal, estate and treatment specific related claims. Case managers or relevant staff could reach out personally to relevant families prior to invitation to claim process as this may help to instil a level of trust and show that the IBCA does care and are committed to assisting families. It's not all about the money but the worst part

	<p>is the not knowing what's going on and having to wait to be contacted. As our mother is blind she is totally reliant on her family to read her correspondence so a "personal human contact approach" could be important to some.</p>
73	<p>Thank you for the Transcript, the Call Summary and the Feedback you intend to provide to others.</p> <p>I think the Feedback Summary is a fair reflection of our conversation and, hopefully, of the strength of my response to this stage of the process. I would like to take this opportunity to respond further and to provide some of the quotes you requested for your feedback summary.</p> <p>Throughout the last few years, since Sir Brian began his Inquiry, I have been under the impression that, in order to assess the amount of compensation to be 'awarded', IBCA would take into account the immensely varied personal circumstances of the Infected and Affected. Not only was this evident during the Inquiry with the number of witnesses (of which I was one) given the opportunity to relay their experiences but this was also implicit in Sir Brian's recommendations to the Government.</p> <p>The Government's own document dated 21 May 2024 included such phrases as:</p> <p><u>'For the majority of applicants, tariffs will be used to calculate compensation. In defined circumstances, a bespoke assessment of individual needs by the IBCA will help to ensure the appropriate compensation is awarded.'</u></p> <p>'Defined circumstances' was not explicitly defined but does suggest that there would be an opportunity for the victims to define them. There is nothing 'bespoke' about how damaged a liver is. It is now clear how restrictive and exclusionary these 'defined circumstances' are. I also understand that it is very likely that few will be successful with the impossible-to-meet terms of the Supplementary Route.</p> <p><u>'AUTONOMY AWARD</u> <u>This award provides additional redress for the distress and suffering caused by the impact of the disease, including interference with family and private life (e.g. loss of opportunity to have children).</u></p> <p><u>This award also recognises the aggravated distress caused by interferences in the autonomy and private life of the eligible applicant.'</u></p> <p>How can you know how much aggravated distress and suffering has been caused by the impact of the disease on this eligible applicant without any information? In my case, I had to undergo and endure 2 rounds of 1 year each of treatment in order to clear the disease. At the time (2001-2004), most people were only subjected to one round of treatment and, in many cases (females, non Genotype 1), they only had to endure 6 months of treatment. How is this even remotely comparable and subject to the same 'award'?</p> <p>Also, due to the timing of my diagnosis and treatments in my personal life, my wife and I 'lost the opportunity to have children'. Where is this taken into account? How is this even remotely comparable to someone who had either already had their children when they had treatment or those who had the relative good fortune to be treated and cleared of the disease young enough to go on to have healthy children after treatment? You don't know about this because it isn't taken into account in your assessment. We are all lumped into the same tariff, based purely on our liver damage.</p> <p><u>'CARE AWARD</u> <u>The award is dependent on individual circumstances, and calculated against a formula based on the typical pattern of care needs for each infection severity band.'</u></p>

Clearly, this award is not dependent on individual circumstances since you have no information of my individual circumstances.

'FINANCIAL LOSS AWARD

The award is dependent on individual circumstances and is calculated against a formula based on the likely impact of an infection and subsequent treatment on an infected person's ability to work through disease progression.'

As above, you do not have the information to assess. You are therefore not taking into account the financial loss and damage done to my career by having to go through 2 rounds of 1 year each of Hell, let alone the various medical problems I have had since (preventing me from working), and continue to have, possibly as a result of the original infection or, even more possibly, due to the harmful effects of 2 years of chemotherapy type treatment on my body. You do not have a formula which takes that into account either.

I note in the updated Government document dated 31 March 2025 that some of these above quotes have been altered. However, I feel the following quotes from the updated document continue to mislead in exactly the same way;

The Government recognises the individuality of the experience of all those impacted by infected blood.

Where is the individuality of my experience recognised?

Whether an applicant is eligible for compensation (and what level of compensation they are eligible to receive) will be dependent on IBCA's assessment of their circumstances.

There has been no assessment of my individual circumstances, just how damaged my liver is/was.

The scheme, as currently designed, is based on flat rates and formulae in extremely broadly defined categories; presumably, to make it quick, cheap and simple FOR IBCA. Not for the victims. That is clear from the discontent expressed by the various patient and community groups who were not consulted on the detailed design of this scheme.

And, even as recently as 14 May 2025, David Foley's update states:

They will work with you to gather all the information needed, so that the right level of compensation is paid as quickly as possible.

'ALL the information needed'? The only information you have asked for is how long I was infected for and what stage of liver damage I have. I call this misleading.

The government/IBCA documents state that you are using tariffs to avoid intrusive questioning and re-traumatisation. TOO LATE. The trauma has been with me every day for the last 25 years since the trauma of the Hep C diagnosis; the trauma of being forced to fight to get even one round of treatment let alone the second one; the trauma of having to tell my partner she may have been infected; the absence of children in my life; the trauma of the trauma of the wrongs done to me and others who for years have not been acknowledged or recognised 'officially' until now; the trauma of giving evidence to the Inquiry; the trauma of feeling I am going to die young having just managed to live etc etc etc. Let alone being taken back, with the diagnosis, to the original medical trauma which caused me to have the 137 Blood Transfusions.

WE VICTIMS LIVE WITH THE TRAUMA EVERY DAY, the trauma of having to fight every step of the way. It's in our bones or, rather, our blood. Our poisoned and poisoning blood.

	<p>I would welcome the intrusive questioning as it would mean SOMEONE was listening and understood just a little bit and might even recognise what I've been through, due to this 'scandal'. Sir Brian's Inquiry gave me hope. IBCA have dashed that hope. ONE MORE TRAUMA to try and live with.</p> <p>I do hope that this email doesn't just result in a change of the wording in your documents to suit your agenda.</p> <p>As mentioned on our call, I would welcome the opportunity to talk to David Foley in person or by phone to discuss this further.</p>
74	<p>I had a coronary by pass operation on the 12 September 1987. This operation was successful , approx a month later I felt very weak with flu like symptoms. On the 6th November 1987 I developed jaundice. Was accepted back into hospital under Dr B.A.Silk and I was diagnosed as having non A nonB Hepatitis.i was discharged and convalesced at home.I was never advised of the seriousness of nonA nonB Hepatitis from any doctor or hospital despite writing to the hospital. I felt very weak until August 1990 when I was recommended to see Prof Diesheiko at the Royal Free Hospital where I was diagnosed as having developed Hepatitis C from the blood transfusion in my operation. My health was not good at this time I felt very weak and on some days very ill that I could not do much but stay at home. On the recommendation of Prof Diesheiko I started a course of a drug called Alpha Interferon and Ribavirin. The consequences of these drugs was that my health got worse, it got so bad that it had to be stopped in March 1991. The consequences of taking these drugs was that I became very violent and short tempered ,I became very argumentative causing tension with my wife and children. I lost my job and my company and I was made bankrupt causing the loss of my house. I lost my will to do anything. To date I still feel generally weak, I have developed allergies and intolerances and I was prescribed to take 125mg Thyroxine as the drugs I was taking destroyed my Thyroid . I have managed to learn to live through these health problems in the last 38 years.</p>
75	<p>Following on from the Inquiry, it is beyond belief that the government have disregarded the final report and recommendations to include the infected and affected community to help build a satisfactory and all encompassing compensation scheme. The recently added Expert Group documents are even more damning and show little reference to what was required by the Inquiry on so many fronts. As previously mentioned we have had to set up a mono haemophiliac campaign group at a time when we are really just completely exhausted and hoped this ordeal was now over. When the government set up the expert group , they excluded a haemophilia expert and the Haemophilia Society. Was this a calculated move or a mistake? Either way this needs to be addressed. There is absolutely no credence in the government saying changing this would add delays to payout , as this can be resolved in parallel to payouts and even with later payments. Its accepting that this wrong needs to be addressed. Resolving this would right the wrong of this forgotten cohort. The mono haemophiliac group has been included in with the transfusion victims to rewrite history and reduce the compensation payments significantly. Our journeys are not the same and this does not reflect the trauma endured from being infected as a child of 8, the stigma , the loss of education and multiple infections as well as being part of unethical research programs. There is no recognition of any infection prior to the age of 16. To give a rough idea on the difference in comparison to HIV infected versus HCV, there is about £1.2 million difference on the base claim, on the calculator I am due £213,000 which reduces as the delays continue, whilst not wanting to take any of this away from HIV sufferers, this disparity is vast and completely unfair and discriminatory. The monthly support schemes for the 2 cohorts are also significantly different. Evidence to the inquiry proved that HEP C is a significant virus and in many cases worse than HIV in modern times and ignores the fact that the government knew that FACTOR 8 was riddled with these viruses and did nothing to protect the haemophiliac community. We are not seeking parity on the care compensation only financial loss to recognise the impact of education and loss of earning potential. Richi Sunak said "it was known these treatments were contaminated", "warnings were ignored" and "they allowed victims to become objects for</p>

	<p>research”, this relates to the haemophiliac group. Nicholas Thomas Symonds said in parliament THIS WEEK, after the inquiry hearings “it is imperative we get this right so that the public can put their trust in our institution which have let down not just the infected blood community”, “a lot more needs to be done” and “as per my evidence last week, I am open to how we can improve the governments actions to ensure we deliver justice for the victims of this devastating scandal”, and “where this is more to do this government will do it”. So will they recognise this forgotten cohort and put this right?</p> <p>I am suffering from severe psychiatric issues brought about from a lifetime of suffering, have PTSD from two rounds of failed interferon treatment and as Jenny said in her questioning, the testimony of interferon sufferers was haunting. I have had to give up work at 55 and I cant believe they actually think that they can get away with saying interferon compensation for this life changing treatment is covered in the core route and not a specific element to compensation. I currently receive SCM and as the inquiry pointed out the compensation and recognition for this has “disappeared” between the 2 sets of regulations. I watched the debate in the Lords for the last set of regulation amendments and they all commented that they were not right but they didn’t want to hold them up so approved them. It is evident that the regulations need some form of revisions to ensure every factor is covered. So have the mono haemos been deliberately left out of the compensation or is this accidental? We are due to have an initial meeting with David Foley and Sir Robert, and at the inquiry Sir Robert suggested we have a face to face meeting to discuss this and now has completely withdrawn from this meeting. At a previous webinar, in mid April, he committed to coming back to us with regards to our question and said he would be looking at our community being forgotten. We need to be heard. With regards to unethical testing, they have selected centres rather than every haemophilia centre. I was given blood tests three monthly from Lewisham after diagnosis and each time they took 4 to 7 vials of blood, this went on for years, I have no idea where they were sent to and as with others, a chunk of these medical records are missing. I was also tested unknowingly for HIV. How do we prove we were lab rats, particularly with comments that we were cheaper than chimpanzees. I believe this became evident in the inquiry but has not been addressed. Evidence was given to the Inquiry that Lewisham was involved in unethical testing but they have not been included in the selected centres. I have met with other campaigners, one who was at Treloars and Lewisham and he can confirm that Dr Mir and Carole Tombs of Lewisham were in liaison with Treloars. I believe all Haemophilia centres should be included. The removal of the 75% payment to partners who have had to limit their careers to provide caring and support is also a disgrace. This was always agreed and now in the last regulations has been dropped, no discussion, just removed! This is particularly distressing as when I die so do my support payments. Is this discriminatory as partners of infected who died prior to 31st March 2025 get this payment. I should have died earlier !!!</p>
76	<p>The infected blood scandal remains one of the most devastating public health crises in modern history. This submission aims to provide a focus on areas of concern that remain and sit heavily with those impacted . This document is structured to address key aspects of concern offering suggested solutions to those concerns.</p> <p><u>1.Speed of Delivery of Compensation</u></p> <p>There is clearly a need for faster delivery with many different valid calls from the infected and affected community. It is disappointing that it has taken too long to implement a process of consideration for those who may be in or approaching palliative care but the process is right that these people should be prioritised.</p> <p>As for compensating those in other groups it might well be appropriate to address those who are older first rather than a random selection. However I believe that there should be a different approach to the affected community. As we know the affected community is much more widespread and can range from the very young to the very old , from the very healthy to the very ill . What we do know is that every affected claim will have to emanate from an infected person , dead or alive. In most cases the affected claims are likely to be primarily an administrative effort . As the government are publicly acknowledging that technology can speed up government work surely this is a prime example of where the technology can be put</p>

in place to speed up the administrative process with the appropriate safeguards in place. Assuming an average infected case will spawn maybe 3 to 4 affected cases under the current core route of regulations, a vast number of claims could be considered in an efficient manner and led by applications process rather than a one to one claim manager approach. The choice of application – manual or technology driven – could be given to the applicant.

Recommendation;

Prioritise payments to those who may be in their final days or months Rather than random selection of victims prioritise by age in all cohorts. Address affected claimants associated with the infected person in the one process or in a parallel process.

HCV Tariffs

Individuals infected through tainted blood products have faced severe health challenges, ranging from progressive liver damage and extra hepatic illnesses caused by Hepatitis C. Many have endured years of uncertainty, chronic pain, and the side effects of treatment regimens. As admitted to by James Quinault in his oral evidence to the inquiry on May 8th 2025:

- The tariffs and eligibility prior to June 2023 was ‘a decision taken by the Government at the time and ministers ‘
- The Government decided in 2023 to establish an expert group in October 2023 and the ministers made those appointments and the ministers took the decision not to appoint someone with psychosocial expertise , clinicians who specialise in bleeding disorders or specialists in blood transfusions.
- One single law firm was appointed by the Cabinet office to provide advice. A firm who works predominantly in defending NHS cases and whose paymasters are the government not just for this contract .
- These processes were ‘not what the inquiry recommended’ and it wouldn’t of have been transparent.
- In conclusion we believe that the design of these tariffs have been flawed and in no way recognise the harm done .

Recommendation:

We believe that a review of the current system should be undertaken with a panel of lawyers , an inclusive group of medical opinions and community members. Essentially what the inquiry recommended but was not followed. This exercise should be independent of IBCA and whilst it is being undertaken IBCA should continue their processes of rolling out under the current compensation framework.

Widows Pensions

Throughout the inquiry Government officials repeatedly stated that no-one would be worse off as a result of the compensation process. In the case of the spouses/partners of those who are currently infected the 75% of the monthly payments needs to be re-introduced . There is absolutely no justifiable reason for taking this away and most who are receiving ‘low’ compensation figures are taking the monthly payments it is unfair that these die with the person without leaving spouses/partners with financial security .

Recommendation:

Re-instate the 75% protection of the monthly payments for those infected spouses/partners upon the death of an infected person

Supplementary Regulations

We were told that the supplementary regulations would be an additional route for those who have suffered above and beyond what the core route covers. It is clear that the Government have used these regulations to save money and only to recognise those who have many severe conditions. When giving evidence ministers and government officials continually refer to core route covering impacts such as fatigue, brain fog etc. I refer to the impacts of the treatment regimens that many undertook and the report that the expert group on Hepatitis produced in 2020 . We have never seen any specific criteria that the core route is covering so after listening to the evidence it is clear in my mind that the core route is in place to address the harm done for the very common and common impacts of the treatment. The government have used the regulations that only addresses a small amount of the very rare impacts. No where is there recognition of the rare and uncommon impacts . This needs redressed as the typical impacts of these treatments have been lifelong in many cases. It is clear that the Jonathon Montgomery expert group have clearly missed the real input of psychosocial experts. In the real world you do not get to see a psychiatrist , you see your GP and psychologists and those impacted by this illness have been totally neglected. Psychologically, victims and their families have grappled with feelings of betrayal, isolation, and grief. For some, the stigma associated with these conditions exacerbated their suffering, leading to strained relationships and diminished quality of life. The regulations do not address the potential of those who have had careers 'halted' and capped limiting their potential earning powers. Many people tried to keep their life as normal as possible albeit hiding secrets from their employees but frequent time off and illnesses will have meant that their career would not have developed as it would have done had they not been infected. Individual centres have been highlighted as centres of unethical research. We know that documents have been destroyed , we know that Doctors worked informally and created 'blood clubs' . We have clear evidence that unethical experimentation was going on in Belfast as highlighted in the Belfast presentations when the Chair noted in that 'dare he say it - -treated as guinea pigs' . Some patients also received F8 bottles labelled as for clinical trials only. We also know that data was exchanged continually with Dr Craske and in the 1960S AND 1970S Belfast was not a reference centre but attached to Oxford centre. Irrespective of dates and whether it was experimentation or research in the balance of probabilities Belfast centre was part of a nationwide program of testing of patients unknowingly which is unethical. For the government to dismiss these facts is just another cost saving exercise.

- 77** The purpose of this submission is to provide a personal perspective on the medical issues and broader impacts stemming from this crisis. As someone affected by the use of contaminated blood products, I am compelled to share my experiences to contribute to the inquiry's understanding and to advocate for justice and accountability.

Medical Issues

The Initial Diagnosis

Like many others, my ordeal began with the use of blood products that were intended to save lives but inadvertently introduced serious infections. The initial diagnosis came as an overwhelming shock. In my case, I was infected with HCV & HBV a condition that would go on to shape every aspect of my life. The medical community, at the time, was unprepared for the scale of this disaster, and the lack of information compounded our fears.

I would like to add further overview on the impact has had on me medically and how I interpret the current regulations , do not meet the intent of the regulations. I do not intend to repeat the many stories or go into deep detail as it is well documented but solely focus on gaps that I see in the current regulations as one infected person .

It is clear that decisions have been made in developing the regulations with a blinkered mindset and without the appropriate input from key stakeholders such as Psychologists,

haematologists , GPs , social workers and the infected. This is truly not right and has shaped a very 'one-sided' set of tariffs and regulations. Frequent dialogue with Government has just resulted in them playing a straight bat and resisting the notion that they may have got aspects wrong.

Issue	Impact	Time of Impact	Recognised in Core Route	Recognised in Supplementary Route
2 periods of Interferon/Ribavirin	Time Off Work , opportunities for progression stalled, opportunity lost for increased financial security ultimately leading to volunteering for redundancy.	Career Lifetime	No	No
Development of Sarcoidosis	Significant time off work, career impact, now on medication for life to control . Defined as an uncommon but definite result of treatment	lifetime	No	No
Dermatological Issues	Common symptom	Lifelong	Yes	N/A
Fatigue, lethargy , generalised pain	Common symptom	Lifetime	Yes	N/A
Gastro issues	Common Symptom	Lifelong	Yes	N/A

	Psychological Impact	Attending psychologist for approx. 5 years and still ongoing as a result of anxiety and PTSD. Still seeing Psychologist. On medication control for approximately 7 years to control impacts. Frequent stress related bleeding episodes.	Lifelong	No	No
	Cognitive issues	Displaying symptoms of cerebellar deterioration. Currently being monitored indicated through brain scans . Definitive link with HCV infection.	Lifelong	No	No

Conclusion

The PM last May stated that the community would get what we deserved and were fully entitled to in his apology. I can only come to the conclusion that we are being treated unfairly and all decisions are based on cost minimisation rather than true recognition of the impacts which just adds to the hurt, anger and frustration felt by many of us. By this stage of the process I had hoped to retire and get a degree of closure to this episode of life but I simply cannot walk away from injustice. The infected blood scandal has left an indelible mark on my life and the lives of countless others. While no inquiry or compensation can undo the past, the pursuit of truth, accountability, and systemic change offers a beacon of hope. By shedding light on the medical issues and far-reaching impacts of this tragedy, I hope to contribute to a future in which no individual or family suffers as we have. This submission is not just a recounting of personal hardship but a call for justice and meaningful reform. Please consider this submission but I would appreciate it if my personal details are kept personal.

