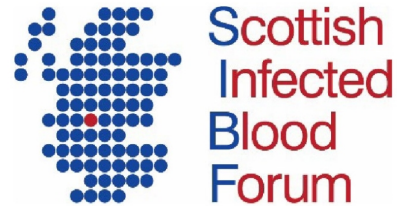


Infected Blood Compensation Reset – A Parallel Process (May 2025)



“A Parallel Process” (this paper) contains a commentary which includes concrete proposals for “getting it right” when it comes to infected blood compensation. It follows the Government’s responses to the Infected Blood Inquiry Reports to date, up to the public hearings on 7th and 8th May 2025. This paper has been prepared by the Scottish Infected Blood Forum.

Introduction

The regulations and associated operational delivery procedures for the Infected Blood Compensation Scheme (IBCS, or “the scheme”) are just **not fit for purpose**. There is near unanimity in that opinion within the community and among all other right-thinking people. The oral testimonies given by a panel of infected and affected community representatives at the Infected Blood Inquiry public hearings in early May 2025 reflected this very troubling situation. These witnesses’ words were powerful, profound, poignant, and compelling. The Inquiry’s forthcoming recommendations require to reflect these apprehensions and be equally powerful, profound, poignant, and compelling. This paper presents the case for a “parallel process” to turn the community’s sentiments into a reasoned, logical, persuasive, practical, and strong proposal for change.

A Parallel Process, and the submission upon which it builds, was compiled after substantial discussion and consultation with SIBF members at the weekly Forum meetings over recent times and via social media. As such, it represents the members’ collective views and not only the SIBF Trustees or Management Committee’s concerns.

The timeframe for dealing with these matters appears to make it almost the last chance for **substantive change** to get the compensation regulations and the scheme corrected for the better. With such an urgency in mind, this SIBF paper covers the following headings:

- Returning to First Principles
- The Wrongs of Government Policy & Process Responses
- A Parallel Process for Getting It Right
- Elements of the Parallel Process Regulations Reset
- Application Filtering, and
- Further Practical Suggestions.

Returning to First Principles

The May 2025 additional oral evidence sessions of the still open Infected Blood Inquiry (“the Inquiry”) included witnesses who were representatives of the Government. Specifically, those appearing were the Rt Hon Nick Thomas-Symonds MP and James Quinault from the Cabinet Office, as well as representatives of the Infected Blood Compensation Authority (IBCA), Sir Robert Francis and Sir David Foley.

From watching and listening to the testimonial responses to questions put to them, it quickly became clear that there was a need to recall – as **a necessary reminder** – the specifically identified basic principles to be applied when forming this particular compensation scheme. Unsurprisingly, the session involving a panel of campaigners and groups did not demonstrate any need to remind them of the vital underpinning principles and findings to guide the development of the scheme of compensation.

The key established facts and principles as the basis for developing and delivering infected blood compensation include the following:

- The **culpability for the harms** caused by the UK/NHS Contaminated Blood Scandal lies with the State, and it was “**not an accident**”.
- The **culpability for the compounded harms** during decades of damaging delays which held up justice, including compensation, also lies with the State, and that was “**not an accident**” either.
- The UK/NHS Contaminated Blood Scandal is unprecedented and **requires an unprecedented response**.
- The scheme and its delivery must be truly **independent**, developed in partnership with the people, **simple** in design, **accessible** in operation, **accountable** to Parliament and the community, **responsive** to concerns, sufficiently **flexible** to specific circumstances, and free from any process which could cause claimants to be re-traumatised.
- The people who are the victim-survivors must be treated with **respect**, allowed **dignity** in their ongoing suffering, they must be **believed**, be **recognised** and **supported**, and they must be fully **recompensed**.
- The impacted community includes all categories of **infected** victim-survivors, all **affected** family member victim-survivors including **carers**, and all the **deceased**. Many people exist in more than one cohort, but regardless of their status, **everyone deserves to be recognised**.
- The infected blood community consists of **people living with bleeding disorders** such as Haemophilia who received factor concentrates, **people given contaminated blood by transfusion**, and those who received **contaminated tissues or blood components**. The viruses were no respecter of persons since the community is representative of all social, cultural, economic, and geographic communities.
- The compensation tariffs must be fair, commensurate, comprehensive, and **fully restorative**. They should be guided by **but not restricted by** any pre-existing tables of damages amounts and categories. Tariffs may be informed by **but not limited by** court derived decisions that may be seen as precedents (because this Scandal is unprecedented). When referring to such baselines,

any consideration of options should always favour the interests of victim-survivors and their families.

- The calculation methodology should mirror the appropriately cited 9/11 settlement concept to encourage community “buy-in” by ensuring **sufficiency in generalised tariff amounts** as opposed to interminably individualised and trauma inducing assessments as would be seen in a court setting. This approach seeks to maximise more generic award levels while minimising any associated legalities. This intentionally more humane and unprecedented way of operating a scheme should assuage any automatic civil servant aversions to spending which might arise from an over-reliance on the “Managing Public Money” text, even during an economic predicament. After all, this really is a “**special case**”.
- Assessment processes and requirements for evidence submission must be **kept to a minimum**, including by making full use of previous scheme documents and decisions where these exist and are supportive. In cases where these are not available, then relying on the “**balance of probability**” approach. Making people go over and re-live their suffering again, while being required to justify themselves with paper evidence again, so it feels like begging bowls are meeting gatekeepers again, is to be avoided at **all** costs (especially human costs).
- **Legal representation** and guidance must be available throughout the compensation claim process, not unfairly restricted, and be financed by the Government.
- **Independent financial advice** must be available throughout the compensation claim process and be financed by the Government.
- **Nobody should be worse off** as a result of the new scheme coming into existence.

The Inquiry has **so far** spent more than six years investigating and delivering a forensic assessment of the Scandal, as it was commissioned by the Government to do. The outcomes from the Inquiry must be respected by the Government since the endeavour followed Terms of Reference approved by the Government. Particular attention must be paid to wholeheartedly accepting and enacting the recommendations as well as taking account of the rationale underpinning each of these. Should the Government not accept any particular recommendation, in whole or in part, then **the reasoning for the rejection must be clearly articulated** and the rationale must be at least as compelling and justifiable as the weight of evidence for making the recommendation in the first place.

The Wrongs of Government Policy & Process Responses

The Government has been caught in the act of **defrauding the infected blood community** of the compensation that is long overdue and doing so just at the point when expectations were highest after the vindication of victimhood was evidenced by the Final Report of the Infected Blood Inquiry. But rather than helping the infected and affected ascend up the final stage of the compensation summit, the Government response has sought to push them off a cliff-edge. People anticipated respite and relief as the promise of resolution approached, but many now report relapse and regression into deeply re-darkened places. The feelings of being politically played, again, are painfully palpable.

From the outset, the Inquiry had been given the topic of investigating **Government responses** to the entirety of the Scandal. The responses of various Governments to the original viral harms and subsequent harms from treatments attracted specific and undeniable criticisms as a result of the Inquiry's detailed analysis of the evidence. However, following the publication of the Inquiry Final Report, it did not take long for the latest responses of Government to cause **similar concerns and criticisms**. It was in recognition of these too similar Government response issues that the Inquiry was forced to schedule the unplanned and unprecedented additional hearings in May 2025 in order to fulfil its remit. The State is still being monitored and its response is still falling very short in its treatment of the infected blood community.

Demonstrating a complete **lack of having learned the lessons** from the original Contaminated Blood Scandal, the Government has continued in its approach of compounding the harms caused by successive administrations by how it has, over the past two to three years, responded to the findings and recommendation from the official, judge-led Public Inquiry. The Inquiry was set up to be the designated advisory body to guide the Government on how to respond to the Scandal. There should have been no need for an array of Johnny-come-lately, selectively appointed, recommendation wreckers who prostitute their professionalism by telling their paymasters what they want to hear.

In this context and in summary form, the more recent compounded harms caused by Government responses is seen by recognising and highlighting the following undeniable truths:

1. It was wrong to establish the Robert Francis compensation framework study with **too little scope for adequate community consultation** (a worrying portent of concerns to come).
2. It was wrong not to **publish the Robert Francis compensation framework study report** according to the original timeline (additional *ibid.*)
3. It was wrong not to **publish a response to the framework study report** according to the original timeline (the pattern of Government compounding the harms now re-established).
4. It was wrong to, in effect, **reject the recommendations in the Second Interim Report** of the Infected Blood Inquiry to immediately set up a properly independent arms-length body with a fully comprehensive panel of clinicians, a specialised panel of infected blood experienced lawyers, and a representative panel of patient/community experts who together would initiate crucial time-saving preparatory work on tariffs and processes, all towards achieving a swift compensation response once the Inquiry had concluded its work.
5. It was wrong to assert what was basically an untruth that the Government “**had to wait**” until **the full report of the Inquiry was published** before it could begin to do anything.
6. It was wrong to continually claim to be “**working at pace**” when that was clearly not the case.
7. It was wrong to enforce an extended period when charities, support groups, and other organisations were **refused access to Ministers** in ways and with the frequency they had previously been afforded access.
8. It was wrong to almost completely **exclude the devolved governments/administrations** even from simply getting to know what was or was not happening in the background.

9. It was wrong to set up **the so-called Expert Group** as a contrived alternative to the recommendations in the Second Interim Report and then to pretend that the objective for doing so was to progress matters of infected blood compensation as quickly as possible.
10. It was wrong to appoint **Jonathan Montgomery** to lead the so-called Expert Group and then not to correct that inappropriate, insensitive, and insulting appointment once the glaring conflicts were pointed out.
11. It was wrong not to include a **sufficient range of experts** on the so-called Expert Group which must surely have produced ill-informed, incomplete, and unreliable recommendations upon which to base any decisions with so great an impact on peoples' lives.
12. It was wrong not to include **representatives of the community** on the so-called Expert Group and to pretend this was an unintended consequence of the way the group was to operate according to the designs of the Cabinet Office.
13. It was wrong only to involve a firm of **lawyers who specialise in defending medical negligence claims** as the sole advisers to the so-called Expert Group, thus exposing the Government's protective and defensive intentions for scheme design. Clearly, the Cabinet Office only wanted to hear legal advice which would minimise the Government's financial exposure, regardless of the additional harms this would cause.
14. It was wrong to have set up the so-called Expert Group to operate in clandestine ways which **avoided any transparency, scrutiny, or accountability**. To hear the Government witnesses add caveats to any belated disclosure of relevant documents (which could be forced upon them by the Inquiry) as a last-ditched attempt to withhold compromising information was wretched and insulting to see and hear.
15. It was wrong for the so-called Expert Group to be said to be **basing its work on the findings of the Inquiry** when it turned out that the members of the group had not considered (or even seen) specific key documentary evidence which should have better informed their deliberations.
16. It was wrong for the Cabinet Office to resist all attempts by the community, including through Freedom of Information requests, to gain **access to the documents** that would likely expose the errors in the thinking of the so-called Expert Group's deliberations, the poor option choices, the curtailed scope for setting fair tariff recommendations, the official and perhaps perfunctory liaison activities between the Group and Cabinet Office policymakers, as well as the less official but more decisively devilish **deal-making liaisons between Jonathan Montgomery and Lord Howe** as revealed during the hearings.
17. It was wrong for civil servants to use the outputs from the so-called Expert Group as the basis for so much of the policy development and decisions related to infected blood compensation. That Group's competency was **fatally flawed** as detailed above, so the undisclosed results of its work would have been seriously compromised by being grossly under-informed and exceptionally skewed. The resistance to making these public only goes to affirm how **the Government must have something to hide**.
18. It was wrong to ignore whole swathes of compensation categories which should attract specific tariff amounts as if the damages caused by these factors was negligible. No intelligent or

rational explanations have been forthcoming for the Cabinet Office's cold-hearted and penny-pinching policy choices not to recognise these categories of damages. These include:

- a. the decades of **compounded harms** which must easily be seen as worthy of attracting exemplary or punitive damages through a specific and substantial category of tariff amounts
 - b. the **extreme and evidentially specified list of harms caused by viral Hepatitis**, beyond the already devastating liver consequences
 - c. the extreme and specific harms caused by **past anti-viral treatments**
 - d. the universality of **research** harms and the hugely significant impacts of these (physically, mentally, and in other ways)
 - e. the very real **CJD** risk raising issues
 - f. the automatic additional living costs of being in an infected household which would have been helped by the recommended **£10,000 per annum uplift**
 - g. the wide-ranging **impacts on the lives of affected family members**, including parents who sacrifice so much to support children, parents who lost children, children who sacrifice so much to support parents, children who lost parents, families who were not allowed to have children, carers who gave up so much as they filled the massive gaps caused by poor statutory provision, and the bereaved generally who still fight for their loved ones – all this being beyond the associated harms to affected people caused by having an infected loved one intrinsically as part of their lives
 - h. the almost incalculable costs paid by **campaigners** who have dedicated and continue to dedicate their lives to support and advocate for the infected and affected community
 - i. these among various other ignored matters to be addressed by compensation, and not least as mentioned by the panel of witnesses representing the community.
19. It was wrong to have senior **Ministers and officials give oral and written evidence** to the Inquiry based on briefings which were clearly designed to reveal as little as possible and cause delay as much as possible.
 20. It was wrong to allow the Prime Minister to say during his "apology" that compensation would be paid **"Whatever it costs"** when he must have already known he did not mean it.
 21. It was wrong to allow the Minister his presentationally generous gesture – purely for the sake of **distracting and distorting the public perception** – the day after the publication of the Inquiry Report. Having him announce a further round of interim compensation actually exposed the untruth of waiting for the full report since a readymade package had obviously been prepared sufficient to get to the point of seeing £310,000 as the maximum compensation payout to some categories of infected people. This pretence of compensatory copiousness nonetheless excluded widows/widowers, the estates of the infected deceased, and several cohorts of living infected victims who had never (and still have never) received any form of financial support or compensation, (such as those infected with Hepatitis B and those who fell foul of wholly unreliable cut-off dates).

22. It was wrong to call a **General Election** without any mitigating action to address or even acknowledge the significant impact on the infected blood community of that announcement so soon (two days) after the Prime Minister made his apology on behalf of the nation to coincide with the publication of the Inquiry Final Report.
23. It was wrong to allow Whitehall a free rein to deal with the fallout (as they would see it) from the Inquiry Final Report. With the calling of the General Election and the automatic proroguing of Parliament, there was **no Parliamentary oversight** for weeks, no opportunity for questions to be asked on behalf of constituents, and no chance to scrutinise or be involved in whatever civil servants were doing during such a critical time in the lives (and deaths) of the infected blood community. The matter was exacerbated by the summer recess shortly after the election.
24. It was wrong for the Government of the day to **apply the whip** to the vote on the proposed amendments to the Victims and Prisoners Bill in a brazen attempt to stymie progress on infected blood compensation.
25. It was wrong for **Parliamentary “dirty tricks”** to be used to overcome the defeat on the Victim and Prisoners Bill by neutering the amendments and minimising question and debate time so that a greatly reduced and more easily manipulated bill had to be passed or not get through the “wash up”.
26. It was wrong for the Government to turn the three-month timescale for establishing a new (pretend) arms-length body to its own advantage by using it as the latest excuse for not allowing meaningful consultation with the community on the arrangements for compensation but instead creating a **“stitch up”**. Without any real opportunity to have meaningful influence, the timeframe arising from **the Victims and Prisoners Bill was gerrymandered** to exclude any involvement from outside the Cabinet Office, except perhaps the Treasury and Number 10. Thus, a deadline which was meant to push the Government to act swiftly was turned back on the victims by a conspiratorial coalition of the Cabinet Office and its fellow penny-pinchers as yet another device to deny them justice.
27. It was wrong to assert that the new body, the Infected Blood Compensation Authority (IBCA), is “independent” and “arms-length” because it is not. Anyone who cites crass line-to-take phrases such as **“operationally independent”** are the embodiment of “a stranger to the truth”, the reciter of a “terminological inexactitude”. The need for **independent oversight by Parliament** is exactly manifest by the way the Cabinet Office has manipulated in its Machiavellian way the establishment of the scheme of compensation and the body set up to administer it. The perpetrator of the crimes, the Government, is being **allowed to set the terms of their own punishment** in ways which minimise the damage from the harms caused and further detriment the victims. The current Infected Blood Compensation Scheme and the Infected Blood Compensation Authority are miles away from justice being done or justice being seen to be done.
28. It was wrong to abuse any trust the community may have placed in **Robert Francis** as the author of the far from perfect Framework Study Report by getting him to rejoin the process through a **tokenistic and completely insincere “consultation process”** as a way of claiming to be involving and listening to the community. His own evidence to the Inquiry flies in the face of what was done in his name.

29. It was wrong to continue to allow Cabinet Office officials, representing the perpetrators of both the original infection harms and the subsequent denial and delay harms, to **internally and exclusively set the compensation levels and access criteria**, and to continue to operate that way even after the realisation of the political pilfering started to be called out.
30. It was wrong to produce **bureaucratically megalithic sets of regulations** which are completely at odds with what is required, then to present these as **a fait accompli** to a community whose expectations had been that they would finally receive the long-delayed justice from a penitent State. Instead, they were presented with a complex contrivance of typical civil service protectionist governmentality allowing minimal scope for making changes unless these were simply tweaks around the edges.
31. It was wrong for officials to deny the strongly held suspicion that **the state of the nation's economy** has caused pressure to be put on high-ticket items of public spending such as infected blood compensation. Nobody believes these denials. Everything the Cabinet Office is doing points to the inevitable conclusion that the order has gone out to minimise financial exposure in every way possible. The infected blood community is being seen as necessary collateral damage in the fiscal crisis, despite the fact that decades of personal financial crises are only now beginning to be belatedly redressed. The timing could hardly have been worse, resulting in the community being victimised by the State, again.
32. It was wrong for the Government to try to weasel its way out of responsibility for the almost complete lack of community consultation in designing the scheme of compensation and delivery mechanism by saying in oral evidence that, basically, **if it were not for circumstances things would have been different**. This is too big a matter to be a hostage to outrageous misfortune. It was not down to poor timing; it was a combination of poor leadership and bureaucratic opportunism at a time when everyone else was excluded or distracted by events such that they could not stop the rot before it took hold.
33. It was wrong to try and involve the community in discriminating against elements of itself by the process of **prioritisation**. The Government made the mess and must take responsibility to fix its wrongs. Trying to stick with a rigid linear programme which forces people to form an orderly queue within a single rank where the further back you are the bigger loser you become because there is only one open window is a narrow-minded and abject failure at creative problem solving. Not involving the community when the process could still have been designed with greater fairness and efficacy has produced a typical civil service botched job.

There are more wrongs than these, as described in other statements, submissions, and documents. Whitehall has made a virtue of never admitting its mistakes, but for the sake of all the terrible harms it caused, has anyone in the Government got the guts to admit to its serial wrongs in this situation?

A Parallel Process for Getting It Right

While it might be easier to call for a complete rejection of the compensation scheme regulations, including the scheme administration process through IBCA, the Government has once again cruelly “forced the hand” of the community by continuing to rely on its old friend, Time. Infected and affected **people do not have the time** to go back to the way the world was when the Second Interim

Report was published. Should the Government now cry that too much water has passed under the bridge and there have already been considerable costs incurred to get to the current position, then that is **a situation of their own making** and must not be allowed to be detrimental to victim-survivors. Any responsibility for dubious delays or spiralling costs – past or future – cannot be placed at the feet of the community, or their support groups and campaigners. That would be classic victim blaming and gaslighting.

No, going back to the beginning is not a realistic option, as the Government has wickedly ensured. But it is also unconscionable to let the Government get away with the rewards of its corporate wrongdoing – past and present. It would mean the Contaminated Blood Scandal was effectively going unpunished and the victims' suffering was being enormously under-recognised. What is needed is a parallel process which allows whatever **usable momentum** there is in the current direction of travel to continue (and hopefully accelerate), while also putting in place a corresponding operational workplan to **remedially move towards a fairer end result**.

The parallelism towards getting it right should involve elements such as:

- additional, **across the board interim payments** for all those registered with schemes and those living infected who have so far been excluded
- **mass registrations** (but with no formal commitment to admissibility until the necessary individual compensation eligibility and calculation processes begin)
- **structural realignment** with the relevant parts of the **Second Interim Report**, including the surgical amputation of the unhealthily incestuous Cabinet Office/IBCA cosy arrangement of two houses for one family
- a **root and branch reconsideration of the regulations** and especially the tariffs/criteria, with this to involve: the community; their recognised legal representatives; and clinical experts from across all the required specialisms
- **slots of time pre-allocated in Parliament** to effect the many necessary changes (which may not be as problematic as intimated, given the examples of Ministerial interventions to make adjustments without recourse to regulatory readjustment as highlighted during the recent hearings)
- activating the **Parliamentary committee process** to oversee progress and remove barriers
- **thematic working groups involving the community** as the real experts on infected blood
- a **buddy system for Cabinet Office and IBCA staff** to work **alongside those in the community** with particular expertise (accountancy related to scheme design, community engagement, clinical components of viral infection impacts, project management, staff training, public communications, etc.)
- ... among other corrective and innovative developments.

The **blinkerred mindset of civil servants** is seen as the main barrier to achieving properly fair and commensurate compensation for everyone who should be recognised as having been harmed by the State. The mostly non-participative attendance at the managed meetings of whole teams of officials has the appearance of them undergoing training in the effective use of civil service smoke and mirrors as they get to observe their more experienced and proficient colleagues at work. Under this

scenario, campaigners and support charity advocates are just cannon fodder to be subjected to a classroom demonstration for underlings as part of their continuous professional development in applying Whitehall's dark arts. An indicator of a shift to **genuine transparency and engagement** towards getting it right will be through allowing Cabinet Office personnel to be exposed to people who have lived experience of infected blood and its consequences. That, and a shift towards **real leadership from Ministers** as they revert to their youthful ideals of getting into public service to actually make a difference and make things better. The community fear that senior civil servants may see their steering of infected blood compensation away from the levels of Government liability that it should reach as a step toward them being rewarded through the Honours system.

Elements of the Parallel Process Regulations Reset

[Note: The following list of reset elements contains some items that are very simply stated while others come with commentaries, some longer than others. Given the general lack of adequate attention being paid by the Government to listening and hearing those most affected by the compensation development process, SIBF believes that no apology is required for the different length of items on the list since it has been considered more important for those who contributed to the content to see that their words were counted as valuable and worthy of being reflected in this paper. Hence the differences in textual content. It should not be inferred that those items which are more concisely listed are any less important to the community – they are not. It is anticipated that many of the matters raised by this paper will be raised by other groups and individuals, and that those issues given less wordy attention herein may well be made up for by the contributions from fellow infectees and affectees from across the community.]

The following list contains some of the required changes in the direction of travel for the Infected Blood Compensation Scheme to be achieved by a participative, planned, and progressive parallel process. A methodology of this nature is the practical manifestation of the imperative towards “getting it right”:

- A. **Independent arms-length body:** Revert to the **truly independent nature and properly arms-length** situation of IBCA and Parliament being the key dynamic, not having the Cabinet Office being free to pull all the levers. The fears of the Government about such a large sum of public funds being too far beyond its control can easily be countered by the fears of the community about such a large sum of public funds being **not far enough** beyond the control of a culpable and insufficiently contrite Government. The determined Government intransigence on this matter must either result in a face-off, or in highly significant trade-offs.
- B. **HIV/HCV/HBC tariff disparity:** Remove the disparities between the specific infection tariff levels and the assessment processes as they relate to HIV infectees compared to Hepatitis infectees. This in no way suggests reducing anything related to the HIV tariffs as a way of achieving parity. The revelation of a sneakily inserted HIV cut-off date exposed during the recent hearings is not acceptable.
- C. **Compensate for compounded harms:** Recognise and pay significant exemplary/punitive compensation for the decades of compounded harms which are detailed by the Inquiry, including: official denials of there being a problem; ignoring advice; cutting costs to the

detriment of safety matters for those harmed; deliberately covering up the scandal by the destruction of evidence; using security concerns to silence reporting; slavishly following untrue lines-to-take such as “we didn’t know”, “they would have died otherwise”, “working at pace”, and “life changing”, etc. It is noted that the compensation for miscarriages of justice lasting over 10 years is capped at £1million, which could be used as a starting point for a new category of tariff. Many people have been imprisoned by viral infection impacts while fighting to reverse injustice not just for 10 years but in some cases for over 40 years.

- D. **IBSS March 2025 deadline:** Remove the unfair deadline of 31 March 2025 for people gaining access to schemes.
- E. **A substantial, standalone tariff for death as a result of infection:** Death is surely the ultimate price paid by someone infected, often going hand-in-hand with long, prolonged deterioration in health whilst loved ones had to keep their family unit together, or had to lie to their children out of a desire to protect them, having to hide the truth from other family members or friends. All deaths must be recognised with a standalone tariff. Without a tariff if this kind that recognises all deaths caused by infection, the Government is being given a free pass to treat these deaths as nothing more than statistics rather than as real people who died as a result of their infections. The death of a wife, husband, long-term partner, parent, child, sibling, grandparent, grandchild, or other significant relationship should be recognised with a top-up payment to the infected deceased estate claim. A comprehensively available compensatory tariff must be to a substantial amount, not the penny-pinching pittance currently being offered.
- F. **Substantial, meaningful, and improved core tariffs for parents:** For most people, parental (kinship) instincts kicks in the second you and your partner discover you are expectant parents. It is an instant love for that baby which includes an elevated desire to protect and nurture the new life. Besides the feelings of joy, there is also trepidation and an often-unspoken hope that everything will be alright. When a health condition like Haemophilia is factored in, or any other health issue, these feelings of wanting to protect your child are amplified and become a core part of who you are as a parent. One SIBF member related, “As a father, I cannot begin to fathom how I would feel having to watch the most precious, incredible miracle that I helped create, suffer in pain and be helpless”. That is considered to be every parent's worst nightmare. Sadly, for many in the community it was a reality. If the Government does not recognise what parents have suffered through assigning a vastly increased tariff, the deaths of hundreds of babies, children, and young people will continue to go unrecognised. It is barbaric, cruel, inhumane, and unacceptable for the Government on the one hand to glibly assert, “We hear you”, yet within the blink of an eye it turns its back on the parents of those whose child, or in some cases children, were killed by the State after giving them contaminated, infected blood. The compensation scheme must recognise what parents have suffered and lost with substantial and meaningful core compensation tariffs.
- G. **Substantial, meaningful, and improved core tariffs for children:** As a young child, suffering the painful loss of a parent, or in some cases parents, denies too many children of their guiding lights in life, cruelly taken from them, robbing them of advice, guidance, support, and so much more. No matter how old you are, your parents are a source of strength, your most accessible role models. Parents are the mostly unsung heroes who pick you up when times are hard. The death, the impacts of a parent's death, on a child's well-being are well documented and well

known. Regardless of a child's age when their parent sadly dies, the infected blood disaster adds a whole other level of harm, suffering, and loss for those children who lose a parent. Having to face the fact that their parent's or parents' death was not an accident or due to natural causes, but instead was a result of State infection(s), or their death was complicated by their infection(s), is a complex, challenging, stressful, life-altering situation for anyone to find themselves in as a child, no matter the age at the time of the parental death. But further, having to live knowing that their life was cut short because a doctor failed in their duty of care or a political choice to save money, and then being made to feel like what you have suffered and lost does not really matter, is once again arrogant, cruel, and screams out in the harshness of recognising that the Government is more concerned about saving money and avoiding precedent than facing the simple truths of its undeniable culpability. There is a generation of people in this country whose lives were, in effect, irreparably destroyed the day their parent died, particularly after having been tumultuously changed during the lead up to their loved one's demise. The compensation scheme must recognise what children have suffered and lost with substantial and meaningful core compensation tariffs.

- H. **Substantial, meaningful, and improved core tariffs for siblings:** As a sibling, losing a brother or sister, or in some cases multiple siblings, robbed so many people of their best friend, their partner in play, their sounding board, their main source of honest and individualised advice, the familial joy from watching a sibling grow with you, starting new families of their own, turning one another into an aunt or an uncle. So many simple pleasures in life, which most people take for granted, were denied to the infected and affected siblings. It is once again, (and this is a recurring theme), nothing short of cruel and demeaning for the Government to suggest that the death of a sibling had a lesser impact on someone because of their age or where they lived. Looking out for your sibling, being concerned for your sibling, and hoping for your sibling or siblings are not defined by how much time you spend together under one roof. Illustrative storylines, where the power of the drama is in the capacity for watchers to identify with the scenarios featured can, repeatedly be seen on various TV series written to mirror true-life situations: For example, two siblings separated by the vagaries of modern living are reunited, sometimes after decades apart. Even after all those years, the bond between those siblings is still there. Just like a parent and child share a special bond, siblings share their own version of just so special a bond. In recognition of this human reality, the current compensation scheme has diluted the impact on a sibling of the death of another sibling by the way the current tariff system has been concocted in such a depersonalising manner. Siblings, for what they have endured and lost, must be recognised if they are ever to feel the death of their sibling or siblings is truly recognised. Like the parents and children's tariffs, siblings deserve meaningful and substantial recognition through amended core tariffs for what they have endured.
- I. **Widow/er support payments:** Restore the right of a widow/widower to receive ongoing regular financial support payments after the death of their loved one. Government Ministers from all four parts of the UK said without qualification that payments were "for life". Provision to remain true to these official commitments has been made for the living infected and so there is no justification for not doing so for the living affected. It was also said, "Nobody would be worse off", or was that nothing more than another sound bite, a temporarily convenient "lie-to-take"? (sic)

- J. **Mitigating “undue delay”:** IBCA should sub-contract out work to IBSS staff to save the scarce resources of IBCA’s staff. (For more detail on this proposed solution, see the Further Practical Suggestions section on page 23.)
- K. **£310,000 Interim payments and IBSS access for HBV victims:** Immediately include those infected with **Hepatitis B** as eligible for IBCA registration and ongoing access to compensation, including in relation to the stark anomaly of interim compensation for these living infected persons. This means making interim payments of £310,000 to all those known to the national schemes, or the Inquiry, or the patient representative groups, or the legal firms. In the same way, provide for retrospective access to backdated support scheme payments from the date of inception of the schemes. IBCA’s David Foley has responded that IBCA does not have the power to make interim compensation payments. Several points arise from this:
- Is IBCA *explicitly precluded* from making interim compensation payments, i.e. do the regulations explicitly prohibit interim payments?
 - Semantically, ‘Interim’ compensation is still ‘compensation’ and IBCA is tasked with making compensation payments to infected and affected people. The substance of the issue should supersede the form of the words.
 - James Quinault said “I think the minister's view would be if it's possible for IBCA to make an interim payment to a group, then that would be clearly a very desirable thing to do since it means that some group, one group of people at least are not waiting right to the end this process to get some of the compensation that they are due.”
 - Does the Paymaster General have the unilateral power to make a decision on this without the need for changes to the regulations?
 - IBCA’s assertion that it would take around 80% of a claims manager’s time to get to the stage of registering and approving interim payments seems erroneous. They are essentially saying 80% of their time is absorbed in performing an IBSS staff role. We assert that the change in “J” above would preclude this uncertain reality from happening and avoid this from being used as a pretext for inaction. The section on Further Practical Suggestions on page 23 provides more detail.
- L. **£310,000 Interim payments and IBSS access for the victims of spurious cut-off dates:** With various cut-off dates having been roundly debunked, immediately include those virally infected, and by association the affected, **where the infection has been deemed as outside of certain cut-off dates**. These living infected persons must be eligible for IBCA registration and ongoing access to compensation, again including in relation to the stark anomaly of interim compensation for these victims. This means making interim payments of £310,000 to all those known to the national schemes, or the Inquiry, or the patient representative groups, or the legal firms. In the same way, provide for retrospective access to backdated support scheme payments from the date of inception of the schemes.
- M. **1972 Hepatitis B test cut-off:** The December 1972 screening cut-off test should be scrapped. The Cabinet office insisted in using an ineffectual testing regime from December 1972 as the basis for eligibility for mono-infected HBV victims getting access to compensation. The Inquiry’s

evidence stated that HBV screening of blood was not reliable until the early to mid 1980's. The Inquiry said

"Whilst in 1972 blood donations began to be screened for Hepatitis B throughout the UK, the screening tests used then were imprecise; Hepatitis B not infrequently continued to be transmitted by blood at least until the early 1980s when screening tests became much improved." (page 146 volume 1), and

"Once it was identified and a test made available for it in about 1970, a universal screening test for donations was quickly introduced by 1972. This was not sensitive enough at first to identify more than around a third of the infective units." (page 5, volume 3).

The 1972 test caught only 1 out of 3 batches of infected blood, 33% effective, i.e. it allowed 2 out of every 3 (66% ineffectual) infected blood batches into the NHS blood supply; a rate which should never be acceptable for a test which should never be used as a universal screener for HBV contaminated blood. By using the 1972 screening date, the Government is not only cutting out swathes of HBV infectees from eligibility and access to the scheme, it is going against the Inquiry's own findings. Cabinet Office insist on additional evidence which for many transfusion infectees will be impossible to provide due to no, missing or destroyed records. On questioning by the SIBF Manager, Cabinet Office said IBCA would have "discretion" in the matter of post 1972 HBV infection. This is an unsatisfactory response and we assert must be corrected by the Inquiry.

- N. **Other so-far excluded cohorts:** NHS patients such as those referred to as "self-clearers" and those infected where this did not convert to full-blown chronic viral disease but who lived curtailed lives in the belief of being so tainted, must have proportionate access to compensation including interim payments, and backdated IBSS financial support.
- O. **Hepatitis "stages":** Completely remove as the only way to recognise levels of viral damage the unjustified, retrogressive, and debunked Hepatitis "stages" of liver damage and instead recognise the array of medically verified extra-hepatic impacts. If ever there was justification for a single, catch-all, generalised tariff, this is it. By far the majority of Hepatitis infectees have experienced a range of serious, debilitating health impacts, sometimes as well as and sometimes instead of liver compromises, even after undergoing the latest and more effective anti-viral treatments. The liver damage impacts are very serious, but so are the co-morbidities associated with the darkly described but correctly christened "slow death" which accompanies viral Hepatitis.
- P. **Cirrhosis, serious scarring, fibrosis:** Promote and stipulate the legal definition of cirrhosis as stated by Inquiry Counsel during the hearings such if a date is required to apply to that liver impact, then the **earliest date** the words "**cirrhosis**" or (*not and*), "**serious scarring**" or (*not and*), "**fibrosis**" are mentioned in medical records should apply. Many IBCA claims managers are using "cirrhosis" only as the triggering word in medical records.
- Q. **Age discrimination:** Remove the cruel age discrimination and pay compensation not for lives lost in childhood but for lives not lived into mature adulthood. Compensation should be restorative not restrictive.
- R. **50% Pension age clawback:** Remove the pension age clawback which appears to treat a pension as equivalent to compensation, somehow. This miserly misapplication of a means-testing

mentality cannot be allowed to stand. It is assumed that the expected considerable savings to the Government by trying to “pull a fast one” like this were considered to be at so lucrative an amount that officials could not help but try it on.

- S. **Deaths of affected people:** Comprehensively review the policy related to those affected people who die before the harms they suffered are recognised through compensation by taking a much more humane approach to estates eligibility (i.e. remove the ridiculously outrageous restriction of them needing to have receive an actual offer). The **Government cannot be free to gain from its decades of delay**, and especially for the more **recent delays** when it most certainly could have acted sooner but **chose not to**. As SIBF member, Caz Challis, said in her testimony at the recent hearings, while the Cabinet Office has been killing time, the associated harms from the viruses have steadily been killing people who the Government knows and admitted in oral hearings are dying before its own scheme will get to them. Saving by slowness means death by design.
- T. **Unethical clinical trials and research harms tariffs:** It is clear that the Government does not recognise, or refuses to acknowledge, how the State and the NHS broke a number of recognised and respected international laws and protocols in relation to the numerous unethical clinical trials and research activities related to infected blood. This whole matter lies at the heart of the Contaminated Blood Scandal. The Government its compensation scheme approach to the tariffs for those used in unethical clinical trials completely reinforces the infamous, degrading, upsetting, and very harmful statement that those used were and still are considered to be “**cheaper than chimps**”. The lessons from history have been whitewashed by the Government and this **sets a very dangerous precedent for what is acceptable harm to innocent people in the name of science**, especially factoring in the many babies and children who were knowingly used, basically as clinical cannon fodder. The current unethical clinical research tariffs must be very significantly increased, firstly to recognise and recompense victims for the very significant damages caused, but secondly, to act as a clear and serious warning to everyone working in the pharmaceutical and healthcare sector that **patient safety and well-being must be the first priority** and those who forget this decree will face serious consequences. To not set the bar high for this tariff sends a clear message to those who undertook historical unethical clinical research that what they did was and still is seen as acceptable. The context for the Nuremberg Code involved innocent people being experimented on within death camps. It was not the fact of them being in death camps which led to the Code. It was the non-consensual, non-communicated, non-regulated use of sentient human beings as guinea pigs to satisfy the curiosity, the commercial, and the combative interests of wicked people and organisations. The current tariffs for unethical clinical research sends a clear message to all scientists, researchers, pharmaceutical companies, doctors, and anyone involved in the fields of developing clinical procedures or medications, that you can do as you wish in the UK without fear of any real repercussions for any harms you may cause. The research damages tariff amounts should be increased by at least a 10 times order of magnitude on the paltry sums currently on the table (i.e., in this situation the tariff amounts should shift from £15,000 to £150,000 as the starting point). Additionally, it must be recognised that all people with a bleeding disorder and some people infected by transfusions were knowingly subjected to unethical research. And further, it was not down to the hospital they happened to attend since these trials were often led by

people in certain centres, but the patient-victims were accessed on a satellite system across the NHS. Inquiry evidence proves this. These research damages were not caused by a sloppy approach to administration in seeking the correct paperwork. They actually descended to a level which went totally **against the Nuremberg Code** and other standards. The semantic wordplay coming from civil servants about “treatments” rather than “research”, and “named centres” rather than “any NHS facility” is disingenuous at best. If this illicit cabal involving Governments, the medical profession, academia, and commercial pharmaceutical companies is justified by some unnamed expert clinical advisor, then that person’s professional competency to practice medicine should be questioned since they are acting against the first rule of the Hippocratic Oath. If this dehumanising death-cult is justified by a non-clinician such as a civil servant, then that person needs to see a cardiologist about a transplant.

- U. **Recognise past anti-viral treatments:** Recognise and compensate specifically and to a properly commensurate level for the hugely detrimental impacts of past highly toxic anti-viral treatments, in particular those involving Interferon or Ribavirin. These were sometimes worse than living with the viruses yet were known to be in some way “effective” in less than 25% of cases. A simple browser search will produce long lists of side-effects, some very serious, yet most people were not warned about what these drugs could or would do to them. Given the toxicity and harms caused, the starting point for this tariff alone should begin at six figures. Also, the idea that a person who undergoes, for example, one of the new direct acting anti-viral (DAA) treatments will automatically be “cured” (a word some clinicians love to use which is another false or at best misleading claim) and miraculously returned to full employability is simply not borne out by the evidence. Further, not everyone who is given the DAA pills achieves a sustained viral response (SVR, which is the more accurate description as opposed to the laziness of saying “cured” or “cleared”).
- V. **Carers compensation:** Thoroughly review care compensation calculations using the evidence of the horrors experienced by carers of virally infected persons over extended periods, costing affected persons’ their livelihoods, social lives, and mental wellbeing. Caring for a sick, seriously ill, or dying family member or friend did not come with a yes or no option. Any decent human being would go out of their way to help care for a loved one or someone who needed help. It is human nature for many to run into a fire, not run away from it. Carers ran into the fire, and many still have the scars, mental and physical, to prove it. Caring for a family member or friend under the circumstances of infected blood added many complexities and impacts that the current compensation scheme has ignored. Becoming a carer for an infected person saw people, mostly with no previous experience, caring for someone who was ill by become their nurse, their taxi service, their bank manager, and more. Many everyday tasks became the responsibility of the carer. For example, tasks that were shared between a husband and wife quickly became the responsibility of the person who was not infected. Often, this involved running and managing their household while managing the household affairs of a loved one or friend. This juggling act usually meant **something had to give**, including time with family, attending special events, or enjoying a quiet weekend at home. Carers faced having to be on call 24 hours a day and knew that if something happened to their loved one or friend because they were not available, it would be a guilt that would be hard to bear. Many parents caring for a child in their family home faced the constant guilt that they were likely infected with a batch or batches of

factor concentrate product which they gave to their child. To then do everything humanly possible as a parent to protect and look after your child, but for their health to deteriorate before your eyes, knowing there was nothing you could do was devastating and traumatising. Living with the daily dread of entering your child's bedroom, fearful that you might find they had died is distressing in the extreme. To find yourself one day sitting by their bedside watching the hopes and dreams you had for your child slowly fade as their breathing became shallow does not bear thinking about. Eventually, they took their last breath as you held them in your arms. And your world, it stopped. With a child's deteriorating health, what was once a family home filled with happy memories and joyous times became a place filled with constant reminders of tears, screams of pain, and worse. Many parents could no longer stay in the home where their child had died, which anyone with a heart could understand. For many families, the indignity of being asked by a doctor or GP to get tested in case they had been infected by their loved one was also present. This is yet another example of the impact an infection has on a wider family, having to both be tested and await results with a sense of dread and worry that another family member might be infected. The people who provided care under these most dire of circumstances did not keep a logbook of how many hours a week they cared for a loved one. How could they when they could not even remain in the job they loved following the career progression they had to forfeit, not to mention the income? What the people who provided care did was brave, selfless, and done out of love and kindness. Carers went well above and beyond the usual boundaries for caring for a loved one, with little to no experience or training, having to quickly find methods and ways of caring that worked for them and their loved one, with minimal support, if anything. **Carers, their circumstances, and what they had to do, must be adequately recognised.** These affected people showed the very best human traits under the worst of conditions. If they had been in the Armed Forces, we would be giving them medals, not punishing them, because they did not keep a log of what care they gave and when. The families and friends who cared for the infected must be recognised with substantial and meaningful core caregiver tariffs.

- W. **Special Category Mechanism (SCM):** If the SCM is not completely replaced by an altogether fairer system, then what remains must provide improved criteria for **infected claimants**, must be changed to include **affected claimants**, and must recognise **all physical and mental health impacts** of all viral infection impacts on infected and affected people. The infected and affected have all suffered profoundly detrimental effects on their mental health due to the infections from contaminated blood. Imagine the anguish of parents who witnessed their child's slow decline, a result of a virus transmitted through a medicine meant to heal, or through blood received during a routine operation. The profound, enduring mental health issues they are left with are a stark testament to the devastating human consequences of infected blood. Consider the life-altering impact on a child, regardless of their age, who cared for a parent only to see them succumb to Hepatitis B or C. The loss of a parent at such a young age leaves a deep, indelible mark, shaping the trajectory of their entire life. How could someone who was informed they had been infected with Hepatitis B or C, a virus with the known clinical outcome of death, not have their life torn apart and then entirely shaped by their infection? Their direction of travel in life under the shadow of their infection, haunting them in every decision they made? From their education, employment, relationships, friendships, every aspect of life for someone infected with Hepatitis B or C changed when they were told they were infected. Or finding a

partner and being constantly worried about infecting them and suggesting they get a Hepatitis test to be asked by a GP "Why did you need a Hepatitis test, is your boyfriend a junkie?" People did not need a formal diagnosis for their infection to have had a massive and negative impact on their lives. Many people went many years without a formal diagnosis. Yet, the effects of their infection had already shaped their lives and who they were as people. How could someone who was infected with Hepatitis B or C, who showed various symptoms that went to their GP for help only to be told they need to change their lifestyle as their blood tests showed signs their liver was damaged and it must be due to them being an alcoholic, even though they didn't drink or only drank very little, **how could being treated like this not have long lasting consequences for someone's mental health?** How could a wife who watched their husband of many years slowly change before their eyes into someone else, as their physical and mental wellbeing deteriorated to the point where the husband they knew was gone and replaced by a shell of a man, fearful of his children seeing him in this condition? How could a wife and indeed the wider family not be left with long lasting mental health issues? Can decision-makers not comprehend the effects of seeing the most significant person in your life becoming weak, confused, angry, in pain, dying, and there was nothing the wife could do to ease or halt this suffering of the man she loved and had been with since they were teenagers but instead having to plan her husband's funeral, be a strong mother to her children, and reassure them everything would be alright when it would not be, because she knew that all their lives would never be the same again? What is now known as the SCM was originally introduced as part of SIBSS in Scotland to allow those eligible to self-declare how their daily lives had been impacted by their infection(s). It was created based on a degree of trust in what the eligible felt and believed, and it allowed the infected to recognise the impact of their infection(s), which was not originally included when SIBSS was set up. However, it is now crucial that the policy change to the SCM recognises and validates the lived experiences of those affected by these infections. As one SIBF member said,

"I am one of the Hepatitis C infected on the SCM under SIBSS. For example, as evidence, I asked my Haematologist to support me with a covering letter, which he did, explaining the type of person I was, as he had looked after me for most of my adult life, along with confirming that the mental health issues I believed I was suffering from would be linked to my infection. This was around 2021/2022, and yet under the current SCM, my haematologist, who is also a recognised clinical expert in the field of hepatology, his clinical opinion does not count. In the last 24 months, I have been put on anti-depressants by my GP to help with mental health and try to regain some control over my life and help me find myself again, as I have felt lost. Feelings of depression, guilt over being alive, flashbacks to my grandfather's [hepatitis C] death, anxiety and fear of being around other people, a great sense of sadness in times when I should be happy and upbeat. There is no escape from infected blood; it is the skeleton in the closet, the dark cloud that hangs over your head every second of every day, even in sleep. It is always there. And yet under the current Mental Health SCM, my GP's opinion is ignored." The current Mental Health SCM requires at least 6 months of psychological counselling and a formal clinical diagnosis by a Clinical Psychologist, which the **Cabinet Office designed to isolate and exclude the vast majority of the infected who have suffered substantial and long-term severe mental health issues.** The reason for the 6-month period is that the drop-off rate for people using mental health services vastly reduces between months 1 and 6. The Cabinet Office will know this fact well. Why is a GP's clinical and professional opinion, or clear written evidence, that a patient is

suffering from depression, anxiety, PTSD, or any other number of mental health issues, not being accepted as evidence? The Mental Health SCM, like the other SCM categories, has been specifically created to minimise both the number of eligible applicants, which is highly complex, and to deter people from applying, with the sole goal of the Cabinet Office to save the Government money. Most people, infected and affected, developed their coping mechanisms for managing their mental health without actively seeking formal or clinical help or support, thus the compensation scheme **must take into account the timeline and context of mental health regarding infected blood**, including time periods and changing social attitudes towards mental health. The current compensation scheme SCM across all tariffs and health impacts is not fit for purpose in terms of the carefully cherry-picked conditions and eligibility criteria for evidence. It must be amended or scrapped in favour of following the same SCM route as IBSS.

- X. **Consideration of historical context of Mental Health:** The current compensation scheme does not take into account the attitudes and perceptions which prevailed in UK society throughout the 1970s, 1980s, 1990s, and early 2000s towards many aspects of the infected blood disaster, one of which is mental health. The idea that anyone infected or affected could have sought help for their mental health, based on today's paradigms, practices, and approaches to mental health does not reflect the tangible and very stark reminder that most people were infected during a time when mental health was still poorly understood and came with a range of stigma and negative connotations. It is well documented that there was widespread stigma surrounding mental illness in the 1970s and 1980s. People with mental health conditions were often viewed as dangerous, weak, or morally flawed, with mental health issues in families rarely being discussed openly, with many families frequently hiding a diagnosis out of shame or fear of social exclusion. Common derogatory language (e.g., "nutcase", "loony bin") reflected the prevailing insensitivity and lack of understanding of mental health issues, which was frequently portrayed negatively in films, TV, comedy, and news, all of which reinforced fear and misunderstanding. Many people with severe mental illness were still housed in large psychiatric hospitals or asylums, often isolated from society. These institutions were usually overcrowded and underfunded, with outdated treatment methods. The idea of "Care in the Community" began to be rolled out in 1983 and promoted moving away from large residential institutions toward support for people living independently. However, implementation was often poorly resourced, leading to vulnerable people being discharged without adequate support, contributing to homelessness and social problems. Although some of the attitudes towards mental health began to change in the late 1980s and into the 1990s, people who had mental health issues related to infected blood, either as someone infected or affected, were already feeling ostracised and abandoned by the NHS, by the state, and sadly in too many cases, by their communities, and even parts of their own families. People did not have the luxury of time to try to deal with their mental health issues when they had a loved one to look after. The infected did not see the point of subjecting themselves to further embarrassment or derision by doctors, having been infected and made to feel like a burden. Many of the infected and affected did not view the NHS as trustworthy or have confidence in the care system. How could they when many asked how they were infected only to be told "we did our best", "we didn't know", "your Factor VIII is expensive so you should be grateful", "you are one of the lucky ones" or any other number of insulting and demeaning responses thrown in peoples' faces when they simply sought answers as to why they or their loved one had been infected and had become so ill. When it

comes to mental health related damages, the scheme must be opened up to change the too restrictive criteria given the circumstances endured by both the infected and affected over so many decades. This includes making it simpler to demonstrate mental health impacts.

- Y. **Financial loss percentages:** Remove the **contrived and nonsensical (20%, 40%, etc.)** financial loss percentages attached to unrecognisable levels of viral impacts over time. As part of the imperative to reach a more realistic, human, and simple process, simply stick to the annual median wage for the relevant years as the baseline constant upon which to recognise financial loss. This entirely “invented” clawback device is entirely the wrong sort of “unprecedented” approach to be taking.
- Z. **£10,000 top-up for ongoing increased living costs and 5% add-on uplift:** The scheme must allow for the restoration of the £10,000 annual top-up and the 5% uplift over the inflationary rate annual increase to reflect the additional cost of living with the impacts of viral infections, the effects of past toxic treatments, the research harms, and other impacts. The typical increases people face which make everyday living more expensive than that of the average UK family includes: heating costs (infected people tend to feel the cold more acutely); diet (part of their recommended better self-management is to have a consistently healthier food intake which costs more); additional cost of insurances (for example, travel companies require full disclosure of health histories which leads to significantly raised charges, and car insurers have higher rates for people who do not work; among other issues. These uplift payments are not some sort of generous bonus to sweeten the hurt caused by someone else’s past mistakes, but is a way of “levelling up” the playing field towards something closer to the economic lives of non-infected people.
- AA. **Interest on awards:** Include for all compensation calculations once completed an additional interest payment for the loss of those monies which would normally be accrued by a person if they had received the money at the time and that money had grown in the normal way, such as by making investments, by the value which is added to certain possessions over time, etc. It has been suggested that the figure of 8% be applied to all completed compensation settlements as fair interest for losses.
- BB. **Annual increases:** Tie annual increases for any regular payments to the **CPIH or RPI** (rather than the lower CPI). For the sake of budgetary planning, this would be expected to mean to the rate as at the September of the year previous to the following new financial year beginning in April from when the annual increase would be applied, similar to the way the IBSS processes have worked
- CC. **Interest for being later in the system:** In light of the inherent unfairness of any prioritisation protocol, there must be a distinct **inflationary interest tariff** to fill the gap for those whose compensation journey begins anywhere other than first in line according to the IBCA prioritisation process. Those towards the end of the line cannot be made to endure more detrimental mistreatment. It is part of the Government facing up to its self-inflicted paucity of progress that it takes responsibility for creating this newer unfairness and provides fair redress.
- DD. **Multiple infections:** The scheme must recognise cases of multiple infections in the calculation of compensation rather than raising the drawbridge of detriments at a co-infection condition that

stops at just two pathogens. The co-morbidities are real and often have a multiplying rather than an additive effect.

- EE. **CJD notifications:** It is important to recognise and compensate for people receiving CJD notifications rather than negating this “inconvenient truth”. Given the lack for so long of a means of diagnosis – apart from examining the brain of a cadaver – this matter has been a “Sword of Damocles” far more impactful than the likes of Lord Penrose recognised.
- FF. **Provide, increase, and back-date funding for charities/support organisations:** Ensure the provision of **long-term** financial support to charities and support organisations who have borne the brunt of the support needs of virally infected people and families. This must be provided for at least as long as IBCA or a subsequent body is operational. The funding should be based on the highest common denominator, for example £500,000 was offered to 3 English charities, such that devolved nation’s charities and groups should not be face any detriment due to smaller size and lower budgets. Since the UK Government makes formulaic funding considerations to devolved nations, the Scottish Infected Blood Forum and Haemophilia Scotland should be recognised commensurately for the advocacy and support work they do. Additionally, SIBF should not be seen as the poor relation to Haemophilia Scotland in the eyes of the Scottish or UK Governments. The funding should be **back-dated** at least to when the Inquiry’s final report was issued in May 2024, to reasonably reflect the nation-wide community angst and commensurate increased workloads resulting from the Government’s appalling and woeful responses. There is a strong case for any backdating to begin from when the Inquiry began due to the greatly increased requirement to engage with the Inquiry as a recognised core participant body. Governments must not be allowed to continue to get ‘blood out of a stone’ from the goodwill shown by charity trustees, staff and volunteers. Staff are burnt out. Harm is being done to the helpers. It is immoral to leave these good people as an afterthought in Governments’ thinking. They are in effect doing the Government’s job at heavily discounted third sector rates of pay, if indeed they are paid: the SIBF manager, who has an unrelated full-time job, has undertaken the weighty task of support without pay for some considerable time. It is politely requested that the reader ask themselves how long you could work 60+ hours per week, including weekends and holidays? How long could you do that without manifesting stress, fatigue and impaired family life?
- GG. **Recognise campaigners:** Restore the concept of an uplift for acknowledged campaigners who have sacrificed years of their lives at great personal expense, including financially, mentally, especially in relation to the huge amounts of time they have given to help the community achieve justice in the face of decades-long Government intransigence. They have borne a very heavy cost, and some have already paid the ultimate price. This specialised tariff category is recognised by a very grateful community as the least that could happen. A very small number have been given honours which demonstrates that at least one facet of Government has recognised the specific and significant value of the contributions by infected blood campaigners. The suggested uplift of an additional 50% added to the value of someone’s compensation is considered entirely reasonable and justified in this respect.
- HH. **Family dynamic supports:** Provide support to situations where family dynamics are more complicated (such as may happen with the estates of deceased persons), especially since many

family and relationship difficulties were caused by the impacts of the infections on real peoples' lives.

There will be other resets required, but the limited time to prepare responses has once again affected the ability of an already compromised community to give matters its full attention.

Application Filtering

It is understood that IBCA have said their updated target is for all registered infected people to be paid, or started their compensation, by the end of this year (2025). Assuming the Infected Blood Inquiry supplementary recommendations are published in, say July/August, that would leave only five or six months of the year for reprioritisation to be impactful.

Under these time restrictions, it would be better for the Inquiry to publish its filtering recommendations immediately after it has considered all responses, rather than wait for the Chair and his team to finish the remainder of their report. To reveal in an earlier timeframe these recommendations would constitute an intervention which would surely make more of a difference.

It was not a fair request for IBCA to seek to involve the community in the development of the prioritisation hierarchy. The aim may have been based on a desire to be engaging, but in this instance it resulted in people having to make nearly impossible choices. It was not so much about who should be first in the queue because they are more deserving (which was already discomfiting), but to be part of the decision about who is to be sidelined and for how long. The apparent need for prioritisation was foisted on the community due to the Government choice to do things the wrong way. It cannot be up to the community to take part in the automatic blame for the inherent unfairness that has resulted.

Thus, without the benefit of seeking either legal support or membership input, the ranking suggestions proposed by the Inquiry appear to be helpful but with one specific exception. This difference of view relates to the living infected who have never had compensation or financial support. It involves, for example, those living infected who have been unfairly excluded/unregistered from the IBSS schemes, and hence from IBCA, because they received the wrong virus such that their rights to seek redress for their wrongs were considered wrong, or maybe they received the wrong infected blood transfusion at the wrong time according to the wrong cut-off dates. These victim-survivors have encountered lots of wrongs – and they still are. So, if a version of the restrictive prioritisation process is to be maintained, then applying its own logic would suggest placing the living infected above the co-infected cohort. But that unsatisfactory scenario is only if the suggestions below are not actioned.

Further Practical Suggestions

The following is a set of suggestions to augment the proposed application filtering put forward by the Infected Blood Inquiry

Proposed action for the living infected excluded

SIBF has been advocating for fundamental changes in approach when it comes to unregistered infectees for over a year and doing so by targeting both the Scottish and UK Governments. In particular, these efforts have focussed around living chronic HBV infectees and living HCV infectees who received blood/products after the September 1991 cut-off point. These are the mainstay of the excluded living infected.

SIBF strenuously advocated for the Scottish Government to amend the eligibility criteria for SIBSS to allow chronic Hepatitis B and post September 1991 infectees to register before the 31 March 2025 imposed cut-off date. The inclusive assertion was in line with the Inquiry's recommendations. On five occasions SIBF met the Health Minister to discuss this, including face-to-face with an excluded HBV member of SIBF in attendance. The Scottish Government decided not to take the appropriate unilateral decision that they could have taken to implement those recommendations. It instead decided to stick with a "four-nation approach", in other words do what Cabinet Office wanted EIBSS to do, which was nothing. Scottish Government Ministers avoided discharging their moral obligation to chronic Hepatitis B infected blood victims. It is asserted that this was motivated by financial considerations and the promise of saving an amount in the region of £17million per annum, with UK Government taking on the SIBSS annual liability until compensation was rolled out. Scottish Government officials, it seems, did not want to rock the Cabinet Office boat. Any other reason seems nonsensical. In a heated exchange, a senior Scottish Government official told SIBF's Manager that the reason for inaction on this was the cost and the uncertainty of the number of people who would apply. So much for discharging their "moral obligation". **The decision was simply immoral.** The SIBF Manager was direct in telling the Scottish Health Minister this and doing so while her officials who recommended that course of action were also there. Clearly, money still speaks louder than morals.

To rectify this fundamental wrong, it is suggested that there be a novel approach to mitigate the "undue delay" and avoid the over commitment of IBCA's scarce staff resources. This would facilitate the expedient registration of the living unregistered victims highlighted above. These suggestions have already been communicated to IBCA and the Inquiry.

It is suggested that IBCA should "**sub-contract out**" (or other similar arrangement) the registration of the excluded folks to SIBSS, EIBSS, etc. so that the staff of the separate support schemes (which will still operate into early next year) can do their **normal registration work** on these unrecognised and unpaid people and then pass them back to IBCA for immediate £310,000 interim compensation. This is in effect what IBSS's did for other living HCV victims before 1 April 2025.

As SIBF member, Caz Challis, said on the Panel at the recent Inquiry hearings:

"It is not our fault if we were infected a little too late or with the wrong virus, or if hospitals lost or destroyed medical notes. We are the living infected excluded from all past and current financial support and interim compensations, now placed at the back of the queue for their compensation process to begin."

It should also be recognised that IBSS staff may require re-training to have attitudes and outlooks homogenous with IBCA's self-professed compassionate perspective on victims. There is justified mistrust in the community of IBSS clinical assessors who have reverted back to Skipton-like mind-sets.

This is also in the context of our knowledge of a recent SIBSS internal review of transfusion applications which were declined, *using EIBSS clinical assessors*, and declined wrongly. The internal review overturned many wrongful application refusals, including, staggeringly, at least one terminally-ill infectee. That person has now recently received compensation (under the existing regulations). Advocates should not have to fight for justice for these people, e.g. to get onto SIBSS; the State and its agents should be discharging this justice by default. At present they are not.

The internal review was instigated and justified by the SIBF Manager who ‘persuaded’ SIBSS and Scottish Government to review and overturn those wrong decisions.

It took repeated sustained robust and forthright discussions to make this happen. Governments can make changes, so long as pervasive reason and logic are not deflected by state-ist attitudes, spin and soundbites.

And regarding HBV, it is important to reiterate:

- there is no “cure” for Hepatitis B, unlike Hepatitis C, (i.e., a sustained viral response after receiving the new DAA medications), and
- those, and other excluded cohorts of people, have never received any financial ex-gratia nor other assistance in the past, nor interim compensation now, and
- there are estimated to be a relative limited number of people in these cohorts who are still alive, and
- the Inquiry specifically recommended Hepatitis B infectees get access to the support schemes.

Proposed action for the elderly or ill affected people

In this area it is asserted that the Inquiry recommendations are deficient, or they certainly have been rendered so by the inaction of Government. This suggestion relates in particular to widow/widowers, partners, and parents of deceased children. Under the existing regulations their own compensation will die with them should they die before their awards are finalised.

It is suggested that another novel approach to mitigate “undue delay” and avoid the over commitment of IBCA’s scarce staff resources could be for IBSS staff to be easily trained to start and progress these affected peoples’ claims up until detailed compensation calculations are required, whereupon IBCA staff can take-over, confirm the information and finalise claims. This is part of a parallel process of work where IBSS’s staff can in-gather, collate, test, and verify information. It would save IBCA staff the often substantial amount of effort and time to do so. A downside is an additional claims officer (from IBSS) being involved in the process rather than a single dedicated claims manager. SIBF recognises how this might be a small compromise, but it would yield a greater net benefit to the compensation awards roll-out process, and most importantly, to those who continue to be excluded and face further detriment by default.

This novel approach is required now because so many affected people are elderly and/or sick themselves and it is sad but reasonable to expect an increasing cascade of deaths in this cohort before 2029.

In Conclusion

At the earliest opportunity, SIBF have forcefully derided the compensation proposals and regulations as promulgated by Cabinet Office officials. At the Consultation meeting chaired by Sir Robert Francis on 18th June 2024, SIBF's Manager said:

- The scheme proposals were “not fit for purpose”
- The Government had “clutched defeat out of the jaws of victory”
- Cabinet Office had “made such an own-goal it was almost unbelievable”
- The “working at pace” mantra was a (repeated) “lie”


SIBF asked Jonathan Montgomery, given the universal negative response to his group's work, if he “could do it all over again, would he do it differently?” He replied, “Yes”, and yet Government steadfastly refuse to redesign or otherwise amend this (purposefully) deeply flawed scheme. SIBF asked if he, or his group, had read Professor David Goldberg's Clinical Review Group Report, commissioned by Scottish Government, and he said “No”. The Clinical Review Group ethos should be followed which would engender a genuinely empathetic approach to scheme design and claims from infected and affected people, rather than the existing DWP-like mind-set which is wholly inappropriate and indeed counter-productive in achieving the Inquiry aims and recommendations.

This mind-set must not be allowed to reign going forward.

Overall, the Government should **return to the original intent of the Inquiry recommendations**. This includes having Ministers and officials accept the corrective need to greatly simplifying the process, significantly increase the tariffs for the sake of fairness and commensurateness, involve the community meaningfully at all points and at all levels, and involve the recognised legal representatives from the point at which each step is in development. Any sense of there being an overriding unaffordability, any suggestion that people are only in it for the money, any downplaying of the deeply harmful detriments suffered, and any hint of a divide and conquer tactic – all of which have been recognised in the Government's approach – must be expunged from the corporate consciousness at Westminster, Whitehall and specifically the Cabinet Office.

Finally, this document is respectfully submitted along with others as a further attempt to have the Government see how it can and must more effectively **shift towards getting it right** when it comes to infected blood compensation. The community remains ready and willing to make it happen.

Contact Details

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The **Scottish Infected Blood Forum** is a Scottish registered charity, SC043464, established in 2012, that supports and advocates on behalf of infected and affected people who received contaminated blood and or blood products, and includes those who received blood transfusions as well as those with bleeding disorders, and their families.