

Infected Blood Compensation: *Getting It Right*

Topic: Correcting the Infected Blood Compensation Scheme proposals and regulations

To: **For Action:** Cabinet Office, Infected Blood Compensation Authority. **For Information:** Infected Blood Charities, Campaigning and Support Groups, Infected Blood Inquiry, Recognised Legal Representatives, Politicians, Devolved Governments, Media

From: Various charities, groups, and individuals concerned with infected blood compensation

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Overview:

This paper has five parts, summarised as follows.

Part 1: Context & Approach

By seeking to engage with Government and the Infected Blood Compensation Authority (IBCA), it must **not** be assumed or reported that the community is automatically in step with the way the Infected Blood Compensation Scheme (the scheme) is being set up. The infected blood community and its representatives see this as **an iterative process**, including those matters which have already gone through Parliament as regulations which are not yet fit for purpose. The aim is to hold fast to what is good, while working collaboratively to change what is not acceptable or workable. The announcement of an initial £11.8bn allocation to infected blood compensation is welcome. It must get to **all** the right people, fairly and swiftly.

Part 2: Unfinished Business

There remain certain key aspects of the scheme and IBCA which are **at odds with the Inquiry recommendations and community expectations**. These include: IBCA being judge-led; being a true arms-length body accountable to Parliament; having two expert panels to support the Chair with the immediate task of resolving the errors emanating from the Cabinet Office so-called Expert Group; urgently initiating a formal programme of meaningful community engagement through a victim/patient expert group; holding a full Parliamentary debate on the Infected Blood Inquiry Final Report; and belatedly publishing the Government response to the original Compensation Framework Study by Sir Robert Francis KC.

Part 3: Main Issues

Some aspects of the scheme are overarching and **highly impactful if not put right**. These issues include: revisiting the so-called Expert Group outputs; noting lessons still to be learnt; gross discrimination in the tariffs setting levels; questionable criteria wrongly applied; the general undervaluing of damages to affected people, carers, and estates; too much reliance on evidence and assessment; returning to the description of the Infected Blood Scandal as being “unprecedented” and so requiring an unprecedented solution; and, addressing the compounded harms caused by the State as a major component of the compensation settlement.

Part 4: Specific Issues to Resolve

A listing of some of the **many problems with the scheme** and certain activities for IBCA to put into its workplan and ways of working. The issues cover aspects such as: provision of paid-for professional support; multiple unanswered questions and points for clarification; various areas of tariff setting that are simply not right; particular cohorts of infectees, deceased or living, not being treated fairly; types of damages to be included; unsuitable calculation methods; tariffs for family carers that disregard the true impact; ways of working with the community including the use of language in communications; and more.

Part 5: Contacts

This includes email addresses for people from a variety of charities and support groups who have agreed to respond to questions or comments from any recipient of this paper. If the contact does not feel qualified to answer, they may pass an enquiry on to someone else. Given that this paper covers many topics and makes many assertions, **it may be the case that not everything included in the text is fully accepted by everyone on the contact list**. This is an iterative process. **Additional contacts can be added** if an updated version of this document is sought.

Context & Approach:

The Final Report of the Infected Blood Inquiry was published in May 2024. The various charities and support groups continue to seek opportunities for close and collaborative working with the UK Government and the IBCA. These actions are on behalf of all infected and affected persons harmed or impacted in the UK, including the estates of the deceased. The work embraces the collective desire to bring out the truth, achieve justice, ensure lessons are learnt, and **facilitate the provision of full and fair recompense**. These matters remain as *“the worst treatment disaster in the history of the NHS”*. (Lord Winston, Hansard)

On the specific and pressing matter of compensation for the multiple damages and losses caused by the NHS Contaminated Blood Scandal, it is acknowledged that the new Labour Government inherited a situation of constant obfuscation, a gross lack of transparency, minimal community engagement, missing budget allocations, and contrived tight timescales. The Government publications of summer 2024 relating to the regulations covering the scheme reflect these past difficulties, while including a few significant and welcome advances.

The activity to achieve timely and comprehensive compensation is viewed as being **an iterative process**, so despite having the added weight of legislative instruments, the Government produced documentation from July 2024 and since is seen by the community as, at best, a somewhat improved second draft, but by no means a finished piece of work, even on the parts of the scheme to which the regulations relate. The IBCA must work within the bounds it has been set and the community expects to do that structurally by formal participation and less formally by various engagement routes. This will cover: organisational establishment and development; strategic and operational direction setting; audit and scrutiny; among other processes. It is to the Government that the community must look for the policy and legislative backing required to improve what has been done inadequately, and to successfully complete the remaining elements of the task by getting those newer parts right the first time around.

The Government has shied away from publicly admitting to rejecting key Inquiry recommendations, relying instead on inaction or different action to show what it is not supporting. This has been possible in part due to the Parliamentary timetable being greatly restricted once the General Election was called just two days after the Inquiry Report was published. This automatically included the proroguing of Parliament for several weeks resulting in a complete absence of oversight and scrutiny when important infected blood matters were being taken forward. Elected members could not advocate for their constituents or the relevant representative interest groups. The Committee system could not hold Ministers to account, so for a crucial period of weeks there were not the usual parliamentary checks and balances. Many individual infected and affected citizens are still facing a situation where their newly elected Member of Parliament does not yet have a constituency office set up, and/or the capacity to hold regular, accessible surgeries, with this situation still existing some six months after they were elected.

Given these crucial caveats to collaboration, then any organisational participation in efforts to move forward with compensation arrangements must not be viewed as an endorsement of what is currently on the table (or on the statute books). There should be no suggestion of unreserved credence or confidence being attributed to the current drafts, regulations, and associated papers, as might be inferred or assumed from the fact of community representative bodies seeking to continue working with Government and IBCA on these matters. As would be expected, the community reserves the right to publicly disagree with and distance itself from any joint work if these efforts will not result in all those infected and affected people who should be included receiving a full and fair compensation outcome as soon as political will makes it possible.

The Chancellor of the Exchequer announced an initial budget allocation of £11.8 billion in the Autumn Statement. This is generally welcomed as a significant sign of progress and intent on the part of the Government. It must be followed by swift action to bring the community to the table in a formal and meaningful way, which will be the most effective approach to “getting it right” from now on.

Unfinished Business:

It might appear to some (or might be the desire of some) that certain matters after having been laid into law, or physically created, or given as a responsibility to named people, are therefore established and irreversible situations. However, it is of crucial importance to assert most robustly that some of these matters remain to be resolved to achieve a satisfactory conclusion from the perspective of the community, despite any assumption of actual or apparent legislative finality. These unfinished matters include the following:

- A. Judge Led & Community Approved: The IBCA must be ***a truly independent judge-led body***, with the Chair role and other senior appointees being referenced to the infected blood community before positions are formally offered. The possibility of Sir Robert Francis continuing in the role of Chair beyond the interim phase is recognised by some as an option. The appointment of interim Directors to IBCA without referring to the community was not a helpful disclosure.
- B. Accountable to Parliament: The IBCA must be ***fully independent of Government by being accountable to Parliament*** and not a Government Department, otherwise it will not meet the criteria or intent for being a properly independent arms-length body. The secondment or

assignment of Cabinet Office personnel to work within the IBCA is seen as a government control mechanism. There has been no demonstration of independence from civil service perspectives, and it would be interesting to understand how these officials see their role. Victims, through their representative groups, are being informed on one hand that the community is unable to arrange access meetings with Ministers, who deflect any approaches over to IBCA. But in turn, IBCA states that it is not able to make independent policy decisions and cannot make changes to the scheme, saying these are matters for the Cabinet Office. It was noticed how the Government scheduled, then cancelled, a "drop-in" for MPs to meet and question key IBCA personnel (for only 45 minutes) rather than have the Government face questions in the Commons. The result of all this is that those impacted have no effective access to Government decision makers other than writing letters, which are often responded to by the use of templates and/or standard lines to take being copied and pasted into an all too brief and inadequate reply which does not address the points raised. The Government acknowledges the scale of the Infected Blood Scandal in words, but in actions the community feels it is still not being adequately consulted with or involved in decisions about the various and ongoing injuries people are facing, and especially how these are to be compensated.

- C. Two Panels in IBCA: The ongoing arrangements and decision-making processes related to all matters of compensation eligibility, tariff-setting, evidence requirements, appeals processes, etc., must revert to the recommendations of Sir Brian Langstaff KC and Sir Robert Francis KC by having the IBCA Chair be supported by two expert panels – one legal and one medical. These panel appointees must be referenced to the infected blood community before positions are formally offered. There is the early requirement for these panels to remedy the many errors created by the inadequacies of the Cabinet Office so-called Expert Group and/or the interpretation of its recommendations by Cabinet Office officials.
- D. Community Involvement: As also recommended, and as a matter of overdue urgency, there must be established a representative group from the infected and affected community (not a single person or three), acting as an expert panel of victim-survivors along with their representatives. This expert panel will **directly support the IBCA Chair and Chief Executive** by bringing to the fore the unique lived experiences through which to view the outputs of any other team of specialist experts. This panel must have **meaningful governance and operational influence** and must include a **range of people** covering the various situations pertaining to the community at large; both communities of interests and of place/geography. The community must be involved in setting the Terms of Reference for this expert panel. Establishing the victim-survivor expert panel would not preclude any thematic advisory groups being set up on matter such as communications and carers issues.
- E. Full Debate in Parliament: There must be a full debate in Parliament (lasting several hours or even days) on the Final Report of the Infected Blood Inquiry, as would normally happen after any Inquiry. The timing of the General Election was simply another example of the infected blood community suffering a detriment by the negative impacts of Government decisions (which certain people must have known about in advance). The full debate will be an opportunity for the Government to acknowledge the shortcomings of the course towards compensation taken thus far, and to recognise the extent of the compounded harms still to be addressed. The ongoing absence of a full debate is an additional, compounding denial of justice and a denial of democratic representation. The debate to comprehensively review and discuss the findings of the Infected Blood Inquiry must be properly announced and victims with their representatives must be given sufficient time to

contact, to meet with, and to brief their elected Members of Parliament to ensure they are properly represented and recorded in reasonable Parliamentary time.

- F. Publication of the Government Response to the Francis Framework Study: For full transparency and contextual understanding, the promised response of the then Government to the publication of the Sir Robert Francis KC report on the Compensation Framework Study must be made public in full. The community needs to know, by right, what was behind the way the Government acted or did not act once this key document was provided. The infected and affected were encouraged to participate in the study and did so in good faith. That good faith must be reciprocated. Publication of the response was promised but is still awaited. The decisions and actions of Ministers and public officials must be open to scrutiny.

Main Issues:

There remains to be rectified a considerable number of problems with the compensation scheme as detailed in the recent documents and pronouncements. These must be fixed before the scheme is fit for purpose and before the IBCA moves further towards operational delivery. It has already been highlighted how, in forming the scheme regulations, the Government may be in breach of laws designed to ensure that certain basic rights are not denied, and that designated protected characteristics are not discriminated against. These include laws related to **Equalities and Human Rights**, among others. The community wishes to avoid formal proceedings such as judicial reviews, but it will not discount such a course of action if participative engagement does not result in significant changes being made.

In no particular order, the main issues include:

1. Expert Group: The so-called Expert Group was the wrong alternative to that of following the recommendations for establishing a proper arms-length body far sooner, and for that body to include the specified expert panels. The situation was exacerbated by the Cabinet Office experts being appointed before the existence of the group was disclosed, by the group not including key specialisms (e.g., haematology, psychology, care, etc.), and by their deliberations being held in secret and subsequently withheld, such that the reference sources, options appraisals, weightings, and other factors were not made public. The Government has also refused to respond to specific Freedom of Information requests to help victims understand how the expert group weighted and designed tariffs and bandings to comply with Equalities and Human Rights laws. It is not possible to know if the experts were simply wrong, or if the officials were just being miserly in selecting from their recommendations, or if it was an im-perfect storm of both. There is also concern with the Government involving in its group a company of lawyers, Browne Jacobson, with a track record in defending medical negligence claims. This is certainly against the spirit of working to achieve a full and fair compensation outcome after the moral case had been accepted. An associated issue remains the appointment of Sir Jonathan Montgomery as the leader of the group. While directing no accusation to besmirch him personally, it is still an insensitive affront to the community for the appointment to have been made and for him to have stayed in the role when the undeniable conflicts were pointed out. This ought to be acknowledged and corrected after the fact. Highlighting the serious problems with this group is essential, but **rather than completely rejecting** all the outpourings from the so-called Expert Group (as many have called for), plus its advice as it has been

filtered by the Cabinet Office, the community seeks to build on whatever can be salvaged from that sorry episode. It is imperative for the community to see **how that group's recommendations and decisions were made** so they can be fully re-assessed, be validated or challenged as required, be better informed, and be remedied as is most assuredly required. The remedial work to be carried out extends from the fundamental basis for the group's thinking to the interpretations derived therefrom which then became the flawed advice to Government. In computer science terms, the so-called Expert Group misadventure has demonstrated a "GI-GO" effect (garbage in – garbage out) since the quality of outputs is determined by the quality of inputs, or lack thereof. Recognising that the Infected Blood Inquiry has not formally closed, it may yet be reasonable for the Inquiry to use its statutory powers to obtain this undisclosed material. It would certainly be an informative and important addition to the public record. For the avoidance of doubt, **the community expects and requires changes to the regulations which have already passed through Parliament** since they are not yet fit for purpose, having been based on the fundamentally flawed process of the so-called Expert Group. The Government needs to publicly acknowledge the error of that approach. The planned second round of regulation setting before the end of March 2025 is seen as the mechanism for this to happen.

2. Lessons Not Learnt, Yet: The essential process of **evidence-based policy making** has been compromised by political expediency and fiscal restrictions. The purpose of the Inquiry was to investigate and uncover the evidence. The purpose of appointing a senior judge as Chair of the Inquiry was to obtain an informed and independent assessment of that evidence. The desire for holding an Inquiry included **the need to learn lessons**, including about the way Governments – Ministers and officials – have handled or mishandled the matters pertaining to infected blood. However, since the publication of the Inquiry Report, the **indications are that the recent Governments have not learnt lessons**, rather it is a continuation of the approach to frustrate accountability, deny participation, minimise financial exposure despite irrefutable culpability, and seek to grind down the victim-survivors, including affected people and those representing estates, into accepting far less than full and fair compensation. It appears that civil servants are still leading the process, are not fully informing Ministers, are sticking to their "lines to take", and are working to the old Machiavellian playbook strategies. The lack of learning lessons seems to cut across Governments and Departments, as highlighted by the Parliamentary Ombudsman, Rebecca Hilsenrath, whose damning report findings in relation to the Windrush Scandal were exposed in the media, including the Guardian which quoted her as saying, "Our report found people who had applied for compensation were being wrongly denied the money they were owed. We found recurrent reasons for this, suggesting these were not one-off issues but **systemic problems**" (emphasis added). The article also noted, "The ombudsman believes that the conclusions from the *Spotlight on the Windrush Compensation Scheme* report could also provide useful lessons for public bodies attempting to offer compensation to people affected by the Post Office and the infected blood scandals." Campaigners have spoken with independent expert compensation scheme lawyers and know there are better ways to do things than what have been concocted.
3. Tariff Discrimination: The extremely discriminating failure to achieve realistic parity of tariffs between infecting viruses and impacts is causing great distress and anger within the community. Put simply, it seems that the terrible consequences of HIV infection are to be recognised, which is undeniably the right thing to do, but the correspondingly terrible consequences of Hepatitis

infections are not being recognised to anything like the right apportionments. The reality is that these days a co-infected person is much more likely to die as a result of their HCV infection than of their HIV infection. This in no way should be seen as a diminution of the impacts of HIV infection. The consequences of living and dying with HIV were and are life-changing and life-limiting in extremely negative ways. The rightful eligibility of HIV and co-infected people to commensurate compensation is **not in question**. The challenge is to the Government in **choosing to discriminate** between viruses. The fact of the higher HIV payment levels being highlighted to the media as if they applied to all people simply goes to illustrate the bare-faced attempts to manipulate the public narrative and paint the Government in a positive light, to the detriment of the majority of the infected and their families. It is also indicative of the tried and tested strategy of divide and conquer which seeks to pit one part of the community against another. It is worth noting how the highlighted cohort of HIV infectees apparently due to receive the higher amounts is by far the smaller in comparison to the total numbers. It is estimated that of the roughly 3,000 people caught up in the infections, the HIV cohort is about 250 people (i.e., 8.33%), thus making it look like their proposed higher payments are a cynical “loss-leader” in marketing terms to achieve a massive overall saving for the Government. The vast **majority of people who have died and continue to die are mono-infected HCV victims** who, in their efforts to secure fair and commensurate compensation, are facing multiple prejudicial actions and inactions by the Government. The criteria people currently appear to be facing is unnecessarily complex, prescriptive and restrictive. This whole area of unfair tariff discrimination is one where legal challenge might need to be considered. Any need for litigation, for example to correct the compounding wrongs of discrimination against mono-HCV victim-survivors, with all the time and trauma involved, would be a dreadful case of a scandal heaped on a scandal. In relation to this specific issue, on 23 October 2024 in the House of Commons, Nick Thomas-Symonds, the Paymaster General and Minister for the Cabinet Office, stated, *“The comparison between HIV and hepatitis C has been raised. For people infected with hepatitis C there are four severity bands, and they are designed in line with clinical diagnostic markers. Recognised health conditions, for example liver damage, have, therefore, been informed by the work of the expert group. It is correct that in comparison there is a single severity band for people infected with HIV. That is because HIV is a lifelong infection. The vast majority of people infected with HIV through blood products have experienced progression to advanced symptomatic HIV disease, including AIDS conditions, and have died as a consequence of the infection. Those who survived continue to be severely impacted by the infection, and the view of the expert group was that it was disproportionately complex and onerous to disaggregate that category into different experiences, and that contrasted with hepatitis, where there is a wide range of experiences, including both acute infections with long-term limited impacts and very serious and ultimately fatal infections. That is the approach, based on the expert group, that the Government have adopted.”* The fatal flaw to this statement which completely undermines its credibility is the reliance on the so-called Expert Group, which was invented/concocted by the Cabinet Office, as the sole source of advice. To highlight just one flaw, it is stated that HIV is a lifelong infection but fails to recognise that the co-morbidities of Hepatitis C are also lifelong, and that Hepatitis B is equally a lifelong impactful issue, too. People with Hepatitis have also progressed to advanced symptomatic hepatic diseases including liver cirrhosis, liver cancer, transplant problems, and **many other incurable and lifelong conditions**. To highlight the death toll caused by HIV whilst at the same time excluding any references to the far greater death toll within the Hepatitis community represents a blatant denial

of the fact that those with Hepatitis infections have and continue to die in far greater numbers as highlighted on page 87 of the (not hidden) Infected Blood Inquiry Statisticians Report. The Government's biased, cherry-picked approach flies in the face of a six-year public inquiry costing millions of pounds with the express purpose of making fully informed recommendations on this and many other related issues. John Glen was simply wrong to listen to his officials and agree to set up the so-called Expert Group. His predecessors in the Paymaster General role were wrong in their decision to ignore the recommendation of Sir Brian Langstaff KC to immediately act to establish the required arms-length body with two proper expert panels so they could begin their preparatory work, but instead the cabinet Office pretended to be "working at pace". The officials were wrong but predictable in proposing a device like the so-called Expert Group as the way forward, and they were wrong in their secretive and restricted selection of those appointed. The so-called Expert Group members were wrong in their recommendations (we must infer this since the details have been withheld), and this wrongness is despite any subject-specific knowledge that they may have de-contextually possessed and then applied in a typically blinkered academic fashion. Nick Thomas-Symonds is wrong to assert without first questioning these new lines to take, and specifically wrong with respect to the already discredited "approach" which must be seen as a choice, and by no means an inevitability since there are alternative and more moral choices which could have been made, could still be made, indeed which must be made. This type of thinking combined with this type of approach has been wrong for over 50 years, and it is still wrong.

4. Invalidated, Restricted & Nonsensical Criteria: Despite knowing better after over 30 years of scheme development and six years of the Inquiry, the Government is opting to adopt retrogressive Hepatitis impact assessment measures which considers "stages" of medically defined damage caused, in this case concentrating only on the liver. This already questionable criteria application is posited as being workable for Hepatitis cases, but with nothing similar for HIV (which would be wrong to attempt to do, despite there existing some delineation parallels in various papers on HIV). These restrictive pre-conditions appear to be a combination of the ill-informed wrong thinking of the so-called Expert Group, exacerbated by the minimisation focus of the Government. It perfectly exemplifies the imperfect outcomes from when two wrongs are pretended to make a right. The science is by no means settled that the impacts of hepatic viruses are exclusively liver-focussed, quite the reverse, in fact, with issues such as brain damage being just one example of the range of severe detriments caused by Hepatitis virus infections. However, it does highlight the erroneous desire to confine the harms caused into one blinkered viewpoint, conveniently **ignoring the considerable detriments caused by the extra-hepatic harms caused**. This is similarly witnessed by other grossly under-recognised or ignored issues such as the **harms caused by anti-viral treatment regimens** and the whole sphere of clandestine **research-derived damages**. Other aspects of inappropriate criteria selection are mentioned below in relation to specific aspects of the tariff-setting debacle.
5. Derisory Treatment of the Affected, Carers & Estates: While it is currently almost impossible to understand (perhaps by design) how the scheme might work in any individual case, it appears quite obvious that the **tariff rates for all the affected cohorts, carers, and those estates to be compensated are wholly inadequate**. Replacing a lost life or a life not lived to its potential is not at all realistically or respectfully represented by what seems to be on offer. It illustrates the enormous extent to which those people making decisions are divorced from the lived – and died – experience

of infected blood. Further, it shows a clear lack of them doing the required preparatory work to fully understand the situations people have faced; at the very least by reading and watching the relevant material from the Inquiry. This has been plainly evidenced when a specific document was referenced in a meeting with IBCA and Cabinet Office staff where it was admitted that this crucially relevant document had not been read or even known about. The almost complete lack of appreciation for the depth and breadth of suffering is blatantly obvious and greatly concerning. No human being could expose themselves to learning about the crushing experiences people have been forced by the State to endure and then come up with what seems to be being offered. The ultimate price of this scandal is death and witnessing it, and the government appears to be not just disrespecting the dead but disregarding the years those that died were forced to live in abject poverty because the government denied its responsibilities. It is not surprising to note the delay in setting the regulations for affected persons into 2025 since what is being proposed is so unsuitable. Unfortunately, the same need to pause to achieve fixes for regulations related to infected people was said to be not possible due to a date having been set (24 August), yet it turned out to be easy to hold back the regulations for affected persons' arrangements. The majority of affected people are excluded from the support schemes and therefore all these delays significantly disadvantage the health and well-being of those denied support. The community is left to draw its own conclusions from the Government asserting two opposing positions at once. It smacks of a crass cost-saving attempt to segregate the suffering of the groups by marginalising those who have lost the most – their child, their parent, their brother, or sister – or who have endured the most. This is another issue with ready application to legal challenge, especially given the paucity and lack of evidence provided about Equalities Assessments.

6. Over-emphasis on Assessment: Even at the core level there is still ***far too much reliance on assessment*** with people having to justify their eligibility for compensation. The situation is even worse for the supplementary routes as currently proposed. The regulations appear to place no limit on the scope and scale of evidence the IBCA might choose to demand. This all seems designed to encourage people to go down a stingy but somewhat easier core route rather than face yet more need to endlessly prove and justify themselves to faceless administrators (case managers), thus being re-re-traumatised in the process. With all the proposed evidence gathering and assessment, it will be important for the community to be reassured that case managers will seek to maximise appropriately all compensation claims rather than to see it as an exercise in minimising any cost to the Government. The whole procedure for gaining access to the scheme is against the intent of the Inquiry recommendations. The possibility for fraudulent claims to emerge is being used to create a blunt instrument to impose further distress on the infected, the affected, carers, and the estates' representatives across the board. ***The core route tariff system was meant to be simple, inobtrusive, sufficiently substantial, and reasonably generic*** to capture as many people as possible into the fast lane of compensation access. The tariffs were meant to adopt the approach of the 9/11 situation so that most people could receive a less individualised compensation outcome but one which they felt was acceptable. The compromises were about time and specificity, not amounts. It was expected that the vast majority of people would be satisfied by a humane core route, with figures such as 80% of the total eligible community being discussed informally as possibly content to go down the core avenue as it was envisaged by Sir Brian Langstaff KC and Sir Robert Francis KC. The supplementary route was to be more of a safety net for those with particular claim issues and

people with less generally definable circumstances. Even then, the applicant was supposed to be trusted in good faith, especially those who have previously sought recognition or recompense. Then the burden was to be on the State to disprove their eligibility. It would be useful for a statement to be issued on the Government's rationale for designing the core route tariff system as it has, and to contrast that with the intended purpose for the supplementary route. The current proposals are in stark contrast to what was supposed to happen. It is as if those drafting the documents have not even read that part of the Inquiry Final Report, or have been told what lines to take, or are in untenable denial. In the context of evidence gathering for assessment purposes, the IBCA should produce **a definitive statement on missing records** as these relate to assessment evidence, not least because the huge number of cases of records not being available causes great anxiety for the community and was such a major element in the Inquiry. IBCA must also be clear about how it will use any documents on people which it receives from the current IBSS bodies or from other sources. Eligible people must not be penalised now for the historical maladministration of the perpetrators.

7. "Unprecedented": There needs to be a **re-emphasis of the "unprecedented" nature of this scandal**. Those who have suffered and are still suffering from the impacts of the UK Contaminated Blood Scandal are now rightly recognised as a special case which must be addressed financially by compensation without the need to take the matters to a damages court (unless a person chooses to exercise that retained right). Before the Inquiry ended, under the sheer weight of evidence and public pressure, the Government finally accepted the moral case for compensation. It was established that those caught up in the scandal should be seen in the light of the matters being truly unprecedented. The process of working out compensation had to be informed by, but must not be limited by, court-based compensation practices and precedents, the various tables of damages, and the context of compounded harms. The task for scheme designers should not be one of minimising or eliminating potential claim criteria, rather it should be looking to pro-actively identify and monetise as many reasonable damages contexts as possible. The aim was not to produce an adversarial process where one side, the Government, was tasked with minimising its financial exposure. The Government must stand by its platitudes and reset the relationship with victim-survivors to one of mutuality for the higher purposes of achieving justice and restoration.
8. Continuing the Compounded Harms: The Chair of the Inquiry frequently referred to there being two tiers of damages for the infected blood community. Firstly, there are the obvious **original harms caused by the infections**, the toxic treatment attempts, the undisclosed research purposes, and the lack of informing people in a meaningful and timely way throughout the period, etc. Secondly, and no less significantly, there are the **equally obvious compounded harms** caused by **successive governments** and their agents. These compounded harms include the systematic destruction of minutes, documents, and files beyond any time-bound protocols, the methodical "filleting" of patient medical records across the whole country, the adherence to official denials, the continuation with unfounded "lines to take", the restricted access to lawmakers and officials, the targeted efforts to keep these matters out of the public eye for bogus national security reasons, and so much more. The Government seems interested only in dealing with the original harms as matters for compensatory consideration, albeit parsimoniously in most cases. However, unlike the original harms being largely historical in nature (but not completely, for example, there are still harms being caused by stigmatisation), **the compounded harms have continued** far beyond the period when people were being injured in a more physical, medical way. The set of concerted cover-up

behaviours, the justice delays equating to justice denial, the spinning of narratives to allow the long grass to grow ever higher has not yet come to an end. For example, the way the Government responded after losing the vote on the Victims and Prisoners Bill, by manipulating the wording and the timetable, is sure evidence that the State is still determined in its intent of further compounding the harms which previous Governments initiated. ***The clock is still running on the compensatory chronometer for compounded harms.*** While someone from the infected blood community dies every three and a half days, someone in IBCA needs to be ***adding an amount to the compensation claim*** to every still living person for ***every day*** the Government continues to harm the community by the way it responds or doesn't respond to the Inquiry Report. The compounded harms side of the equation might be posing difficulties in finding any kind of reference point or baselines upon which to determine amounts of compensation to pay under this huge head of claim, but this should not be any kind of justification to deny the compounded harms culpability or to file the issue under "too difficult to deal with right now". In recognising the extent of the compounded harms, from deliberate maladministration to a level of corporate manslaughter, then it might reasonably be a consideration related to ***punitive or exemplary damages***. The community fear that the officials in control of the development of compensation simply do not comprehend or appreciate the gravity of the past and ongoing hurt caused by Governments for over half a century ("*They just don't get it.*") The State is still harming people today. Government is denying the denial while the community and the Inquiry know why.

While these issues as listed above are already considerable, there are other significant matters to be resolved, many of which are specific in nature. Some of these specific matters are more concisely listed below.

Specific Issues to Resolve:

Given the lack of community involvement in the development of the scheme, any list of issues can only be indicative at this stage. This again highlights the imperative to speak with people across the range of infected blood situations and circumstances to uncover a more comprehensive understanding of the matters of concern. Many of these matters ***could have been avoided*** and much time saved if the Government had followed the recommendation to establish a properly arms-length body before the end of the Inquiry, and to apply the model of two expert groups and meaningful community participation from the start. The sheer number of separate issues listed demonstrates the extent to which the current compensation recommendations and proposals are not fit for purpose. It is feared that there is so much still to fix that some matters, particularly those of interest to a relatively smaller number of people, may fall between the cracks. This would be just another injustice, so it is hoped that the Government and IBCA will work through this list of issues until all are addressed, as well as any others which are not included but are equally important. To suggest that following up on these issues will cause delays when speed is of the essence would be to indulge in corporate victim blaming. The State caused the original harms. The State caused the decades of delays. The State caused the process of responding to the Inquiry recommendations to stall. The State must accept responsibility for putting things right, without resorting to complaints about financial and human resource costs. The State can still show moral courage and indefatigable leadership when it comes to the infected blood scandal. This gauntlet has now been thrown down and awaits a true statesman or stateswoman to pick it up and run with it.

The issues include, but are not limited to:

9. Ex-gratia and Compensation: The need for absolute clarity on **the Government's definition of "ex-gratia"** payments and what these payments are for, and its **definition of "compensation"** and what distinctly that is for. The attempted conflation of meaning and purposes is semantically untenable, and probably legally so, too. The suspicion is that this blended wordplay could deny people full and fair access to monies for past wrongs, current needs, and ongoing impacts. For example, it is stated that those already registered with an IBSS body (who deal with ex-gratia financial support) will "automatically be considered eligible for the scheme" (which is about compensation). Legal representatives have already raised questions about the meaning in law of such broad statements. It must also be made clear the relationship between the IBCA and the four current schemes, including whether IBCA will respect (or not) any previous decisions of the national schemes, including factors such as accepting the self-declaration of SIBSS beneficiaries.
10. Legal Support: The need for clarity about the specific IBCA-funded support available from legal representatives for those seeking to be compensated, from the very start of the process. The cost of this must be fully covered by the IBCA. As information trickles down about, for example, what estates of the deceased might need to do, people are already scrabbling around trying to obtain paperwork and understand concepts such as probate and confirmation. Court officials are directing people in ways that require considerable efforts to try to retrieve information from decades ago, but upon asking a lawyer for help they are told that effort is not required. **Legal support is already overdue**, and it must be for the person to appoint their own legal advisors rather than this being imposed. The situation must not occur where a legal firm will do work up to the amount allocated and then supplement that by charging their client. Further, it cannot be allowed for people to have to pay legal costs up-front and wait for these to be reimbursed. This matter has only recently been the subject of communications from IBCA, but the terms of engagement are far from settled.
11. Financial Advice: The need for clarity about the specific IBCA-funded support available from independent financial advisors for those seeking to be compensated, from the very start of the process. The cost of this must be fully covered by the IBCA. **Independent financial advice is already overdue**.
12. Estates Support: The need for clarity about the specific IBCA-funded support for estates, especially where there are complicated and challenging circumstances. However difficult, the Government and IBCA cannot abdicate their responsibilities for **fixing a problem the State created** by instead going down the route of leaving it up to the families themselves.
13. Hepatitis B: The need to rectify the exclusion of HBV victim-survivors from immediate and ongoing access to monies. This is gratuitous penny-pinching. The reliance on the 1972 screening date has been recognised as unreliable in the Inquiry report. It has been a long-standing omission for HBV infectees to be ignored, while their suffering at the hands of NHS treatments, many of which were not even necessary and none of which were consensually administered, is commensurate with the damages to the HCV group of sufferers. The Inquiry recommended that HBV-infected people be included on the current support schemes, so **it should be central policy to instruct this** rather than allow individual IBSS staff across the four nations to see who moves first – or who doesn't. With disability being a common protected characteristic, this issue may be a matter for legal challenge, if necessary. In Scotland, the justification for not allowing Hep B infected persons into the support

scheme was given as being rooted in the desire to act multilaterally in accordance with the parity agreement. But this claim – to be sticking together to maintain parity – is unfounded. The so-called parity agreement was never written down or established as having a legal basis. In fact, full "parity" was never reached, as can be seen in the differences in treatment by the schemes of widows/widowers in relation to winter payments. Yet the parity argument is used to deny access to Hep B infectees on to the schemes because the four nations claim they want to act multilaterally. The powers are in place for the SNP Scottish Government to accept the recommendation for including Hep B sufferers as recipients of ongoing financial support payments. Given its natural independence-mindedness, it might have been expected that the minor change to facilitate access would have been made by an SNP leadership, but it has not. The suspicion-mindedness of the community has resulted in speculation about deals being done behind closed doors. Across the UK, the number of potentially eligible Hep B people is understood to be small. What could be a quick, reputation-enhancing win for the Government could equally turn into more bad press.

14. Cut-off dates: The need to eliminate the continuation with cut-off dates for eligibility. These do not stand up to scrutiny and are unjustifiably unfair. Similarly, there is no clarity over the significance of "dates of infection", whether these are known, demonstrable in paperwork, inferred, or even relevant. Making people try to identify a specific date is unfair, potentially re-traumatising, and possibly impossible. It is certainly not in the spirit of trusting people, and surely contra-indicated to a generic tariff system which should err on the side of paying rather than withholding. There is some suggestion that the Government would prefer to use an alternative to the date of infection, opting instead for the date of diagnosis. The legislation appears to have been tinkered with to sneak this through at the last minute. Clearly, if diagnosis dates are adopted as the key point for calculating compensation, this would be another unadulterated cost-saving contrivance. This is typical of a mindset where the default is to choose the cheapest option rather than the right option. The rank unfairness of applying cut-off dates only goes to show the callous disregard for the unrecognised suffering of those harmed by the NHS who are ***still being harmed by the State through exclusion***. As with Hepatitis B, it should be central policy to instruct the current schemes to open up to those excluded by erroneous cut-off dates.
15. People Described as Self-cleared or Virally Exposed: The need to include people in compensation terms who appeared to have "cleared" the virus themselves without medical intervention, as well as those who tested positive for antibodies but did not go on to develop a full-blown infection. They might not have spent the greater part of their lives with the actual viruses causing untold harm within their bodies, but ***they were harmed by being exposed and many were poorly advised*** about what it meant. Some of these people felt they had been discouraged from forming relationships or having children and they were compliant with this guidance. They withdrew socially and avoided employment advance. They felt the sting of stigma just like those who would spend most of their lives with a life-limiting infection, while believing and acting to all intents and purposes like an infected person. The claims of people – who still have antibodies – must be respected.
16. Age Discrimination: The need to ***eliminate the age-related cut-off eligibility criterion***. People don't stop suffering when they happen to pass a certain birthday. Worse still, the current position would mean one sibling might be compensated while another sibling receives nothing so that instead of being a postcode lottery it would be a calendar lottery. This may be an example of a zealous over-

- reliance on legal precedence rather than applying the condition of this scandal being unprecedented. It is noted that age is a protected characteristic in law.
17. Pre-working Age Discrimination: The need to recognise and **recompense the losses suffered from before a person reached working age**. The tariff system must be expanded to eradicate this error such that even if losses were not related to earning potentiality due to being too young to work, there were still employment related damages/losses involved. Viral impacts would have negatively affected a person's education, and it is known that compromised academic attainment reduces the opportunities for access to better paid jobs and career progression. As above, this appears to be another example of a zealous over-reliance on legal precedence rather than applying the condition of this scandal being unprecedented. Again, it is noted that age is a protected characteristic in law.
 18. CJD: The need to recognise and recompense the harms caused by people living under **the very real and anxiety-inducing threat of Creutzfeldt-Jakob Disease (CJD)** with this dreadful and potentially deadly disease being another stressor which added to the compounding levels of anti-wellbeing considerations. The tariff system must be expanded to include this issue.
 19. Harms Caused by Toxic Anti-viral Treatments: The need to recognise one of the darkest episodes in the Contaminated Blood Scandal being the use of Interferon to treat hepatic viruses, which later became Interferon in combination with Ribavirin. This is a glaring omission from the components of the compensation package as currently iterated. The Inquiry Report is clear about **the significant harms done by these medications** with minimal expected success rates. Even those for whom these treatments resulted in a sustained viral response, the side effects were severely debilitating and long-lasting, yet the risk were generally downplayed. Whether the original virus was deemed to have been rendered untraceable in the blood or not, people were left with serious physical and mental health impairments for the rest of their lives. These harms must be recognised.
 20. Supplementary Route "Cap": The need to **clarify what is meant by having a cap** on the supplementary route. The lack of knowing what this means is adding further to the anxiety people are feeling. In relation to the Core/Supplementary uncertainties, the Government needs to correct the very clear and discriminatory anomalies in tariffs and the **missing core components** by not putting a limit or cap to the Supplementary route and also by lifting the two barriers to fair and proper compensation: firstly, the statute of limitations in relation to medical negligence claims which is currently set at three years; and secondly, any potential blockage which prevents people being able to bring their own legal claims due to concerns over issues such as "double recovery".
 21. "Prior to Infection": The need to clarify what is meant by the reference to **a timeframe "prior to infection"**. This again piles on the pressure of uncertainty.
 22. Transfusion Cases: The need to recognise the **unique challenges faced by those from the whole blood or transfusion community**. All these people faced their infected blood situation alone and in un-blissful ignorance. There were no charities or support groups for them, as there were for the bleeding disorder community with their information and organisation towards collective action. The transfusion cohort faced a lonely, isolated, prejudiced, stigmatised, and unsupported travail. It must be acknowledged that the State and civil society failed the transfusion victims, and there must be specific compensation for this national neglect. It should also be recognised that of the total

- number of infectees suffering due to contaminated blood, the highest proportion are the transfusion patients.
23. Nuremberg Code: The need to specify the harms being compensated for due to **actual breaches of the Nuremberg Code**. The Infected Blood Scandal included undeniable breaches of the Nuremberg Code and **other international standards**. There must be specific sanctions or consequences for this non-compliance (or even criminality). This aspect of the Scandal must not be ignored as a component of compensation.
 24. Punitive/Exemplary Damages: The need to account for the **deliberate and inexcusable harms caused by Governments for decades**. These acts of commission or omission have caused loss of life, and/or unimaginable loss of quality of life, loss of homes, loss of good health, loss of relationships, loss of jobs or promotion prospects, loss of opportunities normally expected to be available, loss of social relations, and loss of hope. This highlights yet another problem with a conflict of interest. It is bizarre for the situation to exist where compensation amounts which are meant to punish gross misdeeds by an organisation – in this case the Government and its agents – are being adjudicated on by the same culpable organisation, the Government. Where else does the perpetrator get to set the conditions and limitations on their punishment and the victims' access to justice? It will take a morally and politically strong Government Minister or senior civil servant, in the face of inevitable internal resistance, to grasp the nettle of this issue and **recognise that these additional damages are payable**, and in sizeable amounts.
 25. Core/Supplementary Delineation: The need to **clarify the relationship between the core route and the supplementary route**, including an explanation of whether one is exclusive of the other, if they are interoperable, or if the core route can be satisfied to the point of payment so that at least that payment is made rather than the entirety of someone's compensation being held back until the total via the supplementary route is worked out. This issue has been further highlighted once it became known that in the rush (or failed attempt) to get a credible set of regulations ready for 24 August, the research damages aspect has been pushed into the supplementary route. This is seen as concerning since large swathes of people, including the entirety of the bleeding disorder community and many of the transfusion community, should be automatically allocated **a core amount for research impacts** and should not need to provide backup evidence for any research entitlement.
 26. Carers: The need to **comprehensively revisit the tariff amounts for carers and to significantly revise them upwards**. The removal of 25% to non-family carers on claims they were "not professionals" has caused widespread consternation and offence to all impacted carers. It is argued that the Government has basically denied carers the right to work, and now takes the money away without crediting it to carers' National Insurance accounts, denying them proper state pensions. The baseline assumptions and limitations are without credibility when related to the actual lived experience of those who gave up so much of their lives to care for their loved ones, usually with no external support and while experiencing their individual traumas and detriments as an affected person. The proposals appear to assume there was only one carer, but in many situations, it was a necessity to share this familial duty on behalf of the loved one, which could have produced an additionally unique set of difficulties. These are other matters which would best be resolved cooperatively, instead of legally, but the scale of the personal injury award, currently set at £12,000,

shows no proper assessment of the injuries, harms, damages, and detriments sustained by carers. They have suffered excessively, both physical and mental injury. Family carers were also forced to witness and manage unspeakable levels of suffering leaving many with PTSD, other traumatic injuries, and stress-related mental health conditions. These almost intolerable circumstances have resulted in long term physical injuries such as digestive disorders and secondary health problems. The paucity of the award also disregards the hardships endured as a result of the lack of specialist palliative care provision afforded to those so heinously injured. The social impact award fails to recognise the impact of stigma by association, loss of key human rights such as the right to association as well as the right to be free from discrimination, and/or the degree to which the State's failure to take responsibility for those it was responsible for injuring forced family members to subvert their own lives. Additionally, there is the Government's refusal to recognise the loss of the right to have children, which applied to many family members and not only spouses. Then there are losses because carers' own careers had been irrevocably damaged, and the loss of the personal autonomy of carers. All this, when taken together, renders the awards for those affected in this particular way as derisory and degrading in relation to the true impacts. The awards appear to be simply a tokenistic gesture. The Government's reiteration of the phrase, "no amount of money can replace the loss of life", disregards the reality that in so many situations two or more lives were lost, not only the infected one. The compensation should be established in such a way so it will allow victims, especially those unrecognised by the support schemes, to have some form of dignity and quality of life in older age, because several lives have been injured and not simplistically the infected person's mortal life. Compensation is meant to cover the value of the losses sustained by the person who was harmed. How can a small tokenistic gesture replace what should be the full award for recognised mental health injury, such as the £85,000 cited in the original 2022 Sir Robert Francis KC Compensation proposals, but completely and conveniently ignored, either for those infected or affected? The whole proposals around redress for those affected needs to be reassessed and considered with greater recognition of actual injury and social impact. Additional awards for impact where it can be evidenced and bandings attributed, should be included as able to be claimed. The Care Award itself, which was devised without any involvement of a palliative care expert or anyone who provided or currently provides care to infected blood victims, is based on limited false assumptions which include: the perception that care was provided by only one family member, that care requirements followed a linear pathway and/or that 24/7 care was limited to six months. This disregards multiple concerns and actual experiences, and it disregards the Government's own failure to accept responsibility, provide care, or even adequate palliative care. The profound impact on the lives of carers with respect to their mental and physical health is not recognised in the current proposals and regulations. Additionally, a large number of carers who have historically been unrecognised by the support schemes have been discriminated against and have suffered the detriment of neglect.

27. **Back-dating:** The need to involve the community in considering the matter of what and who should be ***eligible for back-dated payments***. The wrongs of the past must not be unrecognised or swept under the carpet, for either those surviving or those deceased. Previous calls to support people which were rejected but have since been confirmed to be unjustified rejections, must be retrospectively resolved. When people successfully appealed a decision, payments were back-dated. The same must apply to those who should have been receiving IBSS support through the

current schemes, as well as payments from the Alliance House organisations. The various means-tested processes where people felt like they were going with a “begging bowl”, only to have their applications rejected, added further to the harms caused by the State. Similarly, the least that can be done is to make all payments eligible since the Second Interim Report was published, including to recognise those affected persons who have died by making back-dated payments from the date of that report to their estate.

28. Scots Law: The need to explain how scheme arrangements will satisfy *the unique components of Scots Law* in ways that will not compromise the compensatory settlements for Scottish victim-survivors, while also not discriminating against the community across the UK.
29. Research: The statements and proposals by the Government on the matter of people being used in research projects and trials are woefully inadequate, as are the proposed compensation levels. It should be *an automatic core route assumption* that every person with a bleeding disorder was subject to clandestine research, and a concomitant core tariff ascribed to them without any need for evidence. Even if there are signed consent forms, it is obvious (and in many cases it can be evidenced) that it was not informed consent. There are also various examples of transfusion patients being unknowingly enrolled in research activities. The suggestion that the research element of compensation be deferred to the supplementary stage is *to deny some of the most serious detriments caused to innocent people, including children*, who came to the NHS in good faith, trusting that their best interests were always at the fore. The amounts of £10,000 (or £15,000 to Treloars research subjects) are *derisory* and show no recognition to those used for research in all the other hospitals identified by the Inquiry. The compensation starting point for this part of the State harms should *begin at an order of magnitude at least 10 times these amounts* (i.e., with starting levels being between £100,000 and £150,000). It is staggering how someone could come up with the figure of £10,000 and think that is reasonable or acceptable. There are also geographical factors to take into consideration, such as the irrefutable evidence that *all* bleeding disorder patients in Scotland were demonstrably and specifically used in various research trials without fully informed consent, or any consent in many cases. Being described as “useful material” simply adds to the toxicity of a situation where innocent people – many being children or already sick people who were supposed to be excluded from such research – became collateral damage in the pursuit of academic and professional advancement, profit chasing, and peer acclaim. There are also questions as to whether differentiating between the Treloars cases and other research projects is in breach of the Equalities Act 2010 and the Human Rights Act 1998 because geography is not in itself a materially protected characteristic in the way disability, age, and gender are. All research subjects appear from the evidence to have been exploited. While it might be asserted that some were more seriously exploited than others, it is not reasonable to rely on a geographic factor alone. The Treloars cases were and remain as horrendous examples of the unethical and potentially illegal use of vulnerable young people as the classic “guinea pigs”. In no way should the very serious detriments caused to “the Treloars Boys” be undermined, indeed it is right for their plight to be particularly highlighted. The children, now just a few remaining men, who were there are specifically and rightly mentioned because of the concentration of children and the available documents related to this. But related research was conducted in other hospitals, specifically including children’s hospitals, all over the UK. It is imperative that the research component of the compensation scheme must not be seen as a chance to divide, but to multiply.

30. Financial Loss Percentages: The tariff provisions for financial losses where these include a percentage of work capacity (i.e., 20%, 40%, 60% and 80% which are analogous to portions of a typical Monday to Friday five-day working week) are a cruel and unusual penny-pinching device. They bear no resemblance to the situations of infected people since this **highly contrived model** takes no account of, for example, the compounding impacts of co-morbidities and the chronic (i.e., life-long and life-limiting) side-effects of toxic anti-viral treatments. The percentage stages broken into fifths must be one of the many aspects of the current iteration of the scheme to be **scrapped entirely**.
31. Not a “Cure”: The assumption that the new direct acting anti-viral (DAA) treatments are a “cure” must be **expunged from the thinking and language** of the Government and the IBCA. The assumption is used in the tariff setting to assert that anyone who has received a sustained viral response (SVR) after a course of these treatments is effectively returned to a working capacity stage. The elevation of wrong thinking on this issue is astounding. It is inaccurate on so many levels, from medical to experiential.
32. Contributing Factors to be Compensated: In devising the tariff system via the so-called Expert Group, it has been impossible for the community to know **the ascribed value of the individual elements of suffering and loss** due to that information being withheld. The community is concerned that in rolling everything into a non-disclosed tariff calculation, then many harm factors will be forgotten or seriously underestimated. It must be possible for IBCA to provide read across tables that detail the specific assigned amounts of compensation to cover, for example: long-term relationship breakdowns; having to abort a baby; foregoing having a family altogether; loss of the family home; significantly curtailed parent/child interactions; giving up a job to be an unpaid carer; seeing the terrible impacts on children without the capacity to succour these; loss of lived awake time due to excessive need to sleep; enduring neighbourhood and institutional stigma; loss of a business; not being able to save or provide a legacy; witnessing the traumatic death of loved ones; being forced to live a lie; (the list goes on). This information must be made available.
33. Annual Uplifts: The Government has chosen to reject a recommendation from two of the most experienced and knowledgeable legal experts on these matters without offering any alternative rationale from some higher source of intelligence. It was not out of sentimental generosity that Sir Brian Langstaff KC and Sir Robert Francis KC decided that the **support payments were to be enhanced by a £10,000 per annum uplift and a 5% increase above the median wage levels**. The reasoning for the uplifts is contained in the evidence, if the decision makers should care to read it. To not include the annual uplifts smacks of more penny-pinching. It is another unjustifiable departure from the recommendations and needs to be corrected by restoring these uplifts. The original plan for the financial support payments was that they should be increased annually in line with the median (not average) wage which was seen as a fair tariff entry point for this group of people, some of whom would perhaps have earned less while others would have earned more had it not been for the infections. However, rather than the recommended uplifts, the baseline will reference the more miserly average wage, while any annual increases would be linked, like benefits, to the September inflation rate determined by the lowly CPI figure (rather than RPI). These are further demonstrations of the Government choosing to minimise compensation by opting for the lesser factors, as opposed to applying the principles the 9/11 settlements. The lack of annual uplifts, the less substantial average wage, and the inferior CPI rate have turned what should have been a

security enabling triple-lock into a victim devaluing triple-whammy. These measures were meant to ensure that the utilitarian and equalising principle of restoring people to the median wage income levels via the general core route calculations was achieved by also taking into account the significant additional costs of living with a viral infection so that the result would broadly equate to a level playing field with the rest of society where these additional costs do not apply. Further, the current iteration of the proposals and regulations do not consider the inheritances that have been lost, nor the impact that clinical trials had on people's ability to work and/or manage money. The annual uplifts are an important component towards achieving full and fair commensurate compensation. Anything less would be an inadequate response and a dereliction of moral duty.

34. Healthy Life Expectancies: There are references to healthy life expectancies as ***some kind of standard for basing calculations***, yet it is known that life expectancies are different across the country. There is no explanation as to how or if these regional differences are to be considered, or why. What is noticeable by its absence is any reference to the mortality data published by the Inquiry, which surely must be relevant. This is another point for clarification and explanation.
35. Stages: The "stages" of liver damage appear to have grown into being made up of four parts when there were previously three stages, but without knowing what this additionality is based on. The reality is that these ***stages should be scrapped altogether*** since they have been roundly refuted as a useful foundation for assessing the impacts of viral infections, particularly as pertaining to the infected blood community. It is concerning that anyone in the so-called Expert Group could get this so wrong since they were supposed to be "experts", but it turned out they asserted a starkly different medical opinion to the one from the publicly known experts involved with the Inquiry. Sadly, but predictably, the Government opted for the ill-informed cheaper route derived from its hand-picked preferred experts and legal advisers.
36. False Impressions of Apparent Generosity: It is disgraceful for the Government to give ***the impression that everyone is getting large amounts of money***. In good faith and with great trepidation, people exposed themselves to the Inquiry spotlight causing them to "go public" with the information of their infections or affected lives. The misinformation about across the board larger settlement levels has resulted in neighbours and "friends" assuming everyone has become a compensation millionaire. If the Government seeks to distance itself from this fake news, it needs to do so publicly rather than try to bathe in the artificial light of having a generous social justice conscience.
37. Transparency: The IBCA has stated it will operate with openness and accessibly. The Cabinet Office also needs to be transparent and inclusive by ***publishing all the documentation*** related to the so-called Expert Group, including the minutes or notes of its meetings, the sources used (or not used), the options considered, and the communications between itself and the Cabinet Office. Several Freedom of Information (FOI) requests have been submitted on these matters, but they have been rejected for what appear to be spurious reasons in an attempt to hide information from those people who could highlight its shortcomings. The disclosures must include any of the group's work since the establishment of the IBCA. FOI requests have not been limited to the work of the so-called Expert Group and its exchanges with the Cabinet Office but have also included other issues such as equalities assessment. It is hoped that IBCA can encourage Governments across the UK to be more accommodating to these entirely reasonable requests.

38. Calculation Tool: There should be **a simple online “ready reckoner”** which people can use to get some idea about what their compensation eligibility could amount to. While it would certainly need to include ***caveats to cover for expected, essential “root and branch” changes to the scheme***, it would go a long way to helping people and families gain a sense of understanding and predictability for future financial planning. They would at least gain an idea of how the heads of terms related to their situation. The lack of a ready reckoner/calculator has caused, and continues to cause, additional untold psychological harm. People have attempted to use what the Government has produced to try and work out what the regulations and further proposals might mean for them in terms of potential amounts of final compensation. Unfortunately, attempts to “do the math” have frequently resulted in people just giving up, with comments being heard like, “I’m lost”, and “I can’t make head nor tail of it, yet I thought my case would be straightforward”. The complexity of Government documents with the lack of clear information, guidance, and support for working out figures for compensation causes immense upset, confusion, and frustration within an already vulnerable community. There should be some kind of call centre (or network of “trusted partner” contacts composed from among the charities and groups) with competent people able to assist enquirers to work out basic calculations such as is done by, for example, The Hepatitis C Trust and the Scottish Infected Blood Forum on a daily basis.
39. Budget: The then Prime Minister, Rishi Sunak, stated from the Despatch Box that compensation would be paid, “whatever it costs”. This should mean there can be ***no absolute cap on the total to be paid out***. However, for the sake of responsible financial planning and management, officials must be working to an estimated budget, at least for this year and looking forward to the next fiscal year. The matter of an undisclosed budget being worked to is causing further distress due to previous experiences of schemes being limited by a budget which officials denied the existence of, and which only became known about long after the decisions were made. Knowledge of there being a large cost to the public purse on the horizon must have been recognised by senior Ministers and officials at least since Penny Mordaunt as Paymaster General highlighted the expectation of there being a substantial cost arising from ***the inevitability of infected blood compensation***. After that, there have been press articles mentioning total sums from £2 billion to over £22 billion. Where these figures came from is undisclosed, although leaks are suspected as a way of frightening people about another large anticipated liability in the face of critical public finances. Hiding the budget is helpful if the aim is to manage expectations downwards, but this should not be treated as a case of not showing the other side the cards you are holding. ***The budget should be up for discussion***.
40. Scrutiny: Without compromising on the call for IBCA to be a proper arms-length body by being accountable to Parliament and not a Government Department, and until that wrong is righted, it will be necessary to ***track the path of accountability covering IBCA and the Cabinet Office through the Parliamentary Committee system***. As a matter of urgency there needs to be ***a statement*** on the arrangements for this scrutiny and ***the timetable*** for it being initiated.
41. Consultancy Communications: Serious concerns have been expressed about a private (Canadian) company which had engaged with the Cabinet Office to market their information management and calculation tool for a compensation scheme. While it is not possible to say much about the tool itself, it is recognised that something of this type will be required. The concerns centre on some of the comments made during meetings with representative groups. The company’s senior representatives have either come at this from the wrong starting point, or they have been given

information by the Government which is at odds with what had otherwise been understood. It was reported by senior company representatives that ***the Government had “accepted” the Inquiry Final Report***, without any qualifications being offered. The company also stated that it ***expects the vast majority of claimants to use the supplementary route, not the core route***, and they were unsettled by the response that over-use of the supplementary route would be an admission of failure in scheme design. The company saw the importance of the system being “lawyer-led”, but that assertion seemed to be designed in a way which effectively excludes the community due to its complex presentation and language. These revelations add to the importance of the community being involved in making the decisions on these crucial business tools and processes.

42. **Conflict of Interest**: Further to the Canadian company proposals, an assertion was made which was in direct opposition to statements made by the Government in evidence to the Inquiry. The company sees ***no role for any lawyers who represented Inquiry core participants*** being involved on the IBCA expert panels. The reason given was the potential for a conflict of interest. However, there was no mention of the role of Government lawyers being involved in crucial aspects of responding to the Inquiry, including in the setting of tariffs which the Government would be liable to pay. That must surely be ***a more obvious conflict of interest***.
43. **HMRC Staff**: Having HMRC as a source of IBCA personnel is very concerning since it is known that they are all ***specifically trained to never invite a claim***. The induction training material for all IBCA staff must include the community in its drafting, and then involve having actual infected and affected people as part of its face-to-face delivery to staff teams.
44. **Apology for What?**: Governments have consistently been unable to describe what previous financial schemes are meant to be addressing in terms of any compensatory component, and previous apologies have ***failed to be specific about what political leaders are apologising for***. The only consistent mantra was that ex-gratia payments were definitely not compensation, presumably to avoid any appearance of accepting liability. But as soon as it became clear that compensation was unavoidable, the race to conflate the two has been swift and unseemly. A key element of any official apology should be ***an acknowledgement that Governments have been deliberately stalling*** any progress towards justice and recompense, including recent Governments. When compensation payments are eventually paid, any remittance advice paperwork should include a detailed description of what exactly it is meant to redress.
45. **Emergency Payments and the Iniquity of Delay**: There should be provision for ***emergency outgoings akin to interim payments***, for example, to stop someone losing their home, or to allow some dignity before the death of those who have waited too long for compensation. Many of the infected and affected are ill, frail, or elderly. The compounding delays to justice and recompense have taken a terrible toll on peoples’ lives. It is cold comfort to know that any payments due to an infected person who dies before compensation is paid out will not be lost to their family since the opportunity is there for an estate claim to be made. The same cannot be said for anyone affected who dies before their rightful compensation is settled. It is an additionally cruel consequence of mortality that there is no provision for the estates of the eligible affected to receive compensation in the event of their demise, despite the suffered damages being commensurate. It has not gone unnoticed how the death of a person automatically becomes a saving to the Government, the same Government which created the scenario of delays, stopping people being compensated years ago.

The potential for making such savings is an obvious disincentive to acting swiftly. With every week that passes, two more eligible people pass away. It would be revealing for a calculation to be made which measures the amount of money the Government has saved by its inaction, for example, since the call for work to commence was made in the Second Interim Report.

46. Interim Compensation to Estates of the Unrecognised Dead: The treatment by the Government of (mainly) parents and children who lost one or more of their loved ones due to the UK Contaminated Blood Scandal has been ***nothing short of appalling***. Being a large part of the cohort who have received nothing from any source of ex-gratia or compensation monies, these family members were nevertheless ignored when the first round of interim compensation was arranged. The arguments about not being registered with existing schemes were harsh and often wrong. It meant that only about one third of deceased infected people had their demise acknowledged, in part. Family members of those without spouses or partners felt their losses were negated, devalued, and disrespected – effectively another element of compounded harms to be compensated for in their own right. Subsequent assurances towards righting this wrong became just broken promises instead of actions, until very recently. However, the route to belated interim compensation has presented as a logistical and administrative assault course, particularly without there having been any provision for legal support, again until very recently. This has caused additional stress and justified resentment. Had the community been involved in rolling this out, many of the difficulties people have experienced could have been anticipated and mitigated against. On the matter of people trying to get ready for estates payments, it is speculated whether the Government had or had not considered issues and potential problems around gathering bereaved families’ details, or which documents might be required for security checks. Pre-registration could have begun as early as 2023, or even since July of this year which might have shown respect and consideration to those excluded estates. Whilst it would help if some higher-level instruction was sent out to, for example, local courts, it has been discovered that there is no uniform way of dealing with matters such as confirmation and probate. In some places it is simple and free, while in other places it is complicated and costly. The community should not suffer another postcode lottery because local systems are different from each other. And this is on top of the problems with staff at the same location giving out conflicting advice to that of their colleagues from the same building, leading to more confusion and frustration.
47. Later in Life Impacts of Infection: The expectation is for people to be compensated fully, particularly when it comes to those who are seeking a single lump-sum payment. However, the scheme needs to have the capacity and longevity to respond to attributable impacts of infections that people are not yet aware of, or which develop ***subsequent to original claim settlement***.
48. Death Certificates: One way some people will approach an aspect of “closure” is to have ***the actual cause of death listed on a revised death certificate***. The Government with IBCA should provide whatever means are needed to the community, including financial if necessary, and issue directives to Coroners Offices to simplify this process so that it is as non-traumatic as possible.
49. Community Engagement: The IBCA must adhere to its aspirations to be inclusive and transparent by ***desisting from arranging meetings where the full range of interest groups and issues are not represented***. Similarly, any charities and support groups that do receive selective invitations should hold back from accepting those invitations until there is an assurance of fuller participation. The

same two-way inclusive transparency must apply to any meetings to be hosted by the Government on infected blood matters.

50. Sample of 20 IBCA Claim System Test Subjects: Heralded as a sign of progress, albeit minimal, the un-consulted announcement of 20 people being selected to be processed for core compensation is viewed with completely reasonable suspicion by the community. While the intentions of IBCA may be honourable, the expectation is that the Government will trumpet how it has met the target of people starting to receive compensation by the self-imposed deadline of December 2024, **conveniently ignoring the fact of there not being any significant bearing on the great majority of the community**. Indeed, once this goal has been “achieved”, it could then be used to reduce the imperative to accelerate towards everyone receiving what they are due. The sample of 20 is seen as tokenistic and has been described as a Wonka-style golden ticket marketing exercise. It was openly acknowledged that the 20 were chosen as being the easier cases, hinting that the aim may be to show delivery being achieved on time, but by targeting “low-hanging fruit” to get some quick wins. Those aware of the range of circumstances people face know that the sampling being limited to 20 people is insufficient to test the system for its capacity to meet the various infected blood situations faced by individuals and families. Questions have been raised about how those selected were known to be the more straightforward cases since nobody has yet given signed permission for their data to be shared with IBCA. Also, given the expectation that the compensation tariff system will be significantly improved, the 20 people must be provided with the caveat that their calculated payment amount will likely be revised upwards, and an additional sum will need to be sent after the necessary regulation changes.
51. Accuracy and Accessing of Personal Data: It has caused considerable collective concern to discover that **IBCA has already obtained all the personal data from the Alliance House organisations** (held together in the name of the Skipton Fund) from Russell-Cooke solicitors. The community had understandably anticipated and assumed that at some point there would be requests sent out to people seeking signed permission from individuals to transfer their personal records from pre-existing financial support schemes, and maybe other sources, to IBCA. For some people this would be the third or fourth time that their personal data had been transferred as previous older schemes were replaced by new ones. Given the sensitivity around record keeping and accuracy issues inherent in the infected blood scandal, it was expected that when requested, the records held by any organisation could be **checked by the person whose data it is** to make sure that errors are not compounded. This seemed like a common courtesy under the circumstances and would avoid the need for someone to go to the trouble of making a formal Subject Access Request (if they even knew they could or what these were). Surely it should have been obvious common sense, not least for the purposes of **building trust with a community that has learned by sad experience to be suspicious** of how organisations treat or mistreat their private personal information, to have forewarned the community that this was going to happen. Was it really necessary to use a barely known about exception within GDPR regulations as the means of securing personal data en masse? In fact, had it ever been intended for the part of the legislation which made this allowance, (and for purportedly public interest justification circumstances), to be used in this way? It has already been commented how the situation has the appearance of a convenience loophole being applied on the “advice” of a Government lawyer. As if that was not bad enough, on top of this the current schemes have very recently written to everyone (they are acting pre-emptively, at least) to say they are

transferring their files to IBCA, apparently to make the process “as simple as possible”. Again, there is no suggestion of people being asked officially to sign over their data. It is known through someone following up on this issue directly, that when it comes to at least one of the schemes, the enquiry was logged but no guarantee was given about the data transfer being stopped if a person so wished. It was also noted that among the information to be shared is a list of every amount of money a person has received from the scheme. People are asking why IBCA needs this particular piece of personal information since it has already been established that previous ex-gratia payments will not be taken into account when calculating someone’s compensation. It is not too great a leap of suspicious concern to wonder if this move could be a backdoor method of accessing such detail for nefarious purposes which would result in further savings to the Treasury coffers, despite assurances to the contrary. For all those connected to the scandal, the issue of records and their safekeeping is triggering for a host of obvious reasons. So, this approach to data transfer, allegedly to make things “as easy and quick as possible”, could be an own goal as far as building trust with the community is concerned. How could this have happened without being seen as potentially problematic, and during a time when engagement meetings were being held with the very people who could have helped to facilitate the process? After everything that has been learnt through the Inquiry, and with the Inquiry itself highlighting the fact that those in authority had taken a paternalistic attitude towards the community and made decisions on peoples’ behalf without first consulting with them, yet this is still happening through the transfer of personal information/data from Russell-Cooke solicitors to IBCA, and from the IBSS schemes to IBCA. This transfer of personal information/data already has been and is being carried out without a single beneficiary being asked to provide written authority for the transfer. The phrase “nothing about us without us” is relevant here and should have been applied, but again it looks like decisions are being made on peoples’ behalf without them being consulted, and in the case of the Russell Cooke information, without anyone even being contacted before the transfer was made.

52. Unanswered Questions: A small number of meetings were held in June 2024 with representatives of the charities and unincorporated support groups. The timing did not allow for all the issues people had to be considered, but **a commitment was given that the unanswered questions would be answered afterwards**, including both the questions raised in the discussions and from the video conferencing platform’s chat function. However, this did not happen before the IBCA recommendations were passed to the Government, and as of early November 2024 the **answers have still not been provided**. A “high level” summary of the meetings was produced, but this was a “highly selective” list of topics which were apparently brought up and included sweeping statements about people being generally supportive of various actions by IBCA and the Government. However, **the document is not a true reflection** of the matters raised and basically ignores those issues which the community is most concerned about. A meeting was also held with recognised legal representatives, but no summary of that meeting has been provided. There needs to be a **re-drafting and re-issuing of the high-level summary** after it has been approved by attendees to more accurately reflect the discussions. It should also be distributed with **an attachment which fully answers the questions** thus far unresolved. Many but not all of the unanswered questions re-appear in this listing.
53. Language Sensitivity: There needs to be more considerate use of language, particularly because these “words matter” because of the subject, and particularly when they are part of what appears

to be *the latest line to take*. One current example is the use of “*life-changing*” to describe the anticipated amounts of infected blood compensation as if it applies to everyone. It is perhaps ironic that the same phrase, “*life-changing*”, is used by the Police to describe the more serious end of the spectrum of injuries that a victim of a crime has sustained such as limb loss or facial disfigurement. It was the infections that were life-changing. In the attempted flip to positivity, life-changing sounds more like a sound-bite spin phrase to pitch to an undiscerning media short on background fact checking. It has become an unwelcome and unhelpful trope that is akin to the previous disingenuous phrase, or lie, “*working at pace*”. Similarly, people are already uncomfortable when making contact with IBCA and being referred to as “*customers*”. This is another context where issues could have been pre-emptively dealt with by earlier community involvement in the operational development of the scheme and IBCA. Most recently, in relation to the latest interim payments to the unrecognised estates, a person called to explain the difficulties in obtaining evidence after so many years had passed. They were insensitively told, “Just gather the information and send it in”. This type of response is without any recognition of the trauma that doing so will bring up again, especially when this type of documentation will have been requested various times by various bodies, often to no avail. Further, and also recently, there has been the use of social media such as *YouTube* to portray IBCA and the Government in good light to society at large, rather than simply speaking directly to the community. In a parallel mis-communicative way, it is also important to note how the IBCA “interim” period is itself causing additional stress and frustration. Contacting IBCA seems to be a call-centre lottery because the people may be pleasant enough, but their subject knowledge is sadly lacking. They don’t know anything more than the community. It is as if people centrally are making things up as they go along. There are also reports of personnel from the financial support schemes saying they too are not being kept up to date any more than people are through the emailed updates, with these updates often being just repeats of other mailings.

54. Bland (non-)Responses: Campaigners and groups have been frustrated by the manner in which raised concerns and questions are responded to, or rather, are *deflected* by non-committal word salads, the habitual over-use of lines to take, and other linguistic sophistry. The Inquiry was able to cut through some of the previous examples of “Yes, Minister” letter formats, but the time for that must be over, at least when it comes to matters of infected blood. It would certainly be a worrying sign of *infiltration and entryism by planted civil servants* if responses from IBCA were seen to adopt such practices when responding to genuine communications from the community.
55. Facilitating Access to Processes: For years the infected blood community has suffered unfair treatment when required to interact with various statutory and other bodies, mainly due to ignorance and a lack of joined-up working. This has included: problems obtaining healthcare; applying for or renewing benefits payments; securing insurance and other financial products; accessing court-based resources such as probate; dealing with tax affairs; among a variety of others. The main problem is the lack of understanding about infected blood impacts and how to deal with ex-gratia payments or compensation, for example, in relation to means-tested benefits or tax. Even nowadays, individuals from the community are still facing difficulties with front-line officials from these types of bodies who are making draconian demands, such as requiring complete lists of every penny of previous ex-gratia or compensation payments. Others are literally being told to stand at their front door, with their spouse, and take a “selfie” while also holding up the photograph page of

their passport. Despite the payments from the various schemes supposedly being excluded from means-tested benefit calculations, there are still instances of members of the infected blood community being called in for questioning – or more precisely, the ominously sounding confrontation of them being “interview under caution” – by DWP fraud investigators. Too many have suffered financially as their ex-gratia lump sum payments were wrongly taken into account against their means tested benefits. This happens because the DWP has access to the bank accounts of individuals on means-tested benefits and they cross-reference savings/interest payments against the records of those claiming benefits. The larger ex-gratia lump sums, which included the £20k and £50k payments for Hepatitis C, will automatically trigger an alert within the DWP resulting in individuals being called in for questioning and treated as if they are benefit cheats. This has led to some individuals having to repay what the DWP class as an overpayment. The sorrowful outcome is that some peoples’ lump sum compensation payments, which should have been for the benefit of an infected individual to use as they wish, are effectively being paid back to the Government. It appears this issue has mainly affected the Hepatitis community, and particularly the non-bleeding disorder cohort, since the HIV community (who in this context are predominantly people with a bleeding disorder) have benefitted from their established networks. This includes the Haemophilia Societies and through events like The Macfarlane Trust “men only” weekends away. These groupings would normally have shared among the participants the information about letters or other resources available to them confirming the need for agencies to exclude support payments from being considered for benefits and tax purposes. These could then be used to inform the DWP that any monies they received should not be taken into account in respect of means-tested benefits. This information was generally not available previously to those with mono Hepatitis C, and particularly has not been known about by non-bleeding disorder individuals or even haemophiliacs who were not involved with the societies. These examples are seen to be a more recent form of stigmatisation, bordering on harassment. To counter such incidents, **instructions should be prepared and circulated** by IBCA and/or the Government to go to the various bodies to advise them about how to deal with a person presenting with an infected blood related matter. Perhaps the internal systems used by these agencies can have a special code or flag with a link to instructions for all cases of infected blood interactions with officialdom. It may also be helpful to have **a named person**, either within IBCA or the organisation itself, who understands the issues and whose contact details are circulated for ease of reference. Further, there are examples of the existing schemes providing letters to mortgage lenders and IBCA might usefully prepare similar standard letters. The charities and support groups are able to assist IBCA as trusted intermediaries in the eyes of the community who can be conduits for information such as that recently raised by Sir Robert Francis KC in relation to IBCA hearing about potential money-grabbing legal or consultancy firms offering “no win, no fee” deals with high percentage costs if they do “win”. IBCA cannot tell people what to do or who to engage as representatives, but the charities and groups can convey concerns to the community to help avoid people being ripped off. Doing this should also attract some remuneration or retainer-type arrangement since again it allows IBCA to do its work more effectively.

56. Real Changes and Partnership Working with Community Representatives: Part of the non-financial compensation component is to see **meaningful and lasting change** in the way organisations and people operate. There is a need for **financial resources to charities and representative groups** to

facilitate a coordinated approach to allowing the surviving infected and affected community to **seek responses from certain bodies** so these organisations can both acknowledge the wrongs of the past and describe how these can never happen again. The organisations include (among others): blood transfusion services; the UKHCDO; the civil service; research universities and their linked teaching hospitals; teaching schools; professional associations; relevant expert advisory groups; etc. Additionally, the charities and support groups are uniquely placed and trusted by the community as conduits for communications and facilitation of supported access to services. Some of these groups are being heavily pressured by concerned **people seeking advice and information, and currently much of that relates to IBCA**. The additional and unfinanced expectation must be recognised and provided for. Where there are paid staff, this matter has become extremely challenging. Similarly, those acting voluntarily are having to use their own resources to meet the new need. Paradoxically, there are two charities that are completely under-utilised at present. With the vast wealth of information and experience they have about the community, IBCA (and/or the Government) should be paying these organisations specifically for regular feedback and support, thereby ensuring meaningful community engagement is taking place. While resourcing these groups is not a direct compensatory matter, it is seen as a means of helping IBCA achieve its objectives.

57. Information to Elected Representatives: There needs to be IBCA financial **resources provided to charities and support groups** to allow them to prepare, produce, and distribute **information packs and banks of questions** to inform all MPs and Lords, particularly those new to Parliament, from the perspective of the infected blood community rather than leaving such communications up to Parliament and professional lobbyists. Funding this activity would assist IBCA towards providing the best service possible.

As stated previously, there will be further issues requiring to be resolved on behalf of particular groups of victim-survivors. There is an **open invitation** to those with specific knowledge or experience related to aspects of the scheme development which are not included above to **suggest additions to what is listed herein**.

In addressing these matters, it should be remembered that the **infected and affected community includes** those with the knowledge, skills, and lived experience to guide officials towards achieving the best outcome and to get it right first time from now on, as opposed to what has happened thus far.

The community remains ready and willing to work collaboratively as equal partners on these matters.

Contacts:

The collection of those who contributed to this document includes some who wish to remain unnamed in relation to their involvement in activities connected with the UK Contaminated Blood Scandal. This includes by them submitting their evidence to the Infected Blood Inquiry anonymously. To comply with this position and in some cases due to legal restrictions, not all names of the contributors are included herein.

This paper covers many topics and makes just as many assertions. As stated, the likelihood is understood of there being potentially more issues which are not included, yet. It is further recognised that there may be differences in views or nuances of expression between individuals and representative groups on

specific topics presented in the text, but it suggested that on the majority of topics people can coalesce around the need for these items to be addressed. So, in the spirit of this being an iterative process, anyone or any group who wishes to contribute publicly to the development of the compensation scheme through this paper is invited to add their contact details below. ***Being listed as a contact would be on the explicit understanding that those who appear may not agree with everything put forward in this paper.*** To be added to the list of contacts, should an updated versions be sought, you are hereby invited to make this known to any person already listed.

Any recipient (***minister, parliamentarian, journalist, official in a statutory body, or other***) of this paper who wishes to discuss a matter arising from its content, please contact any of those whose names appear below. Should that contact feel they can respond themselves, they will try to do so as soon as possible. Enquirers should be aware that many of those who are active on these issues are unpaid volunteers who will likely be impacted as an infected or affected person themselves, and this fact of their daily lives can cause delays in responding. Please also note, if the enquiry subject matter is beyond the scope of knowledge of the contact, they may pass your details and enquiry on to someone with specific topic knowledge.

Contacts include:

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- Rachel Halford, CEO (The Hepatitis C Trust): Rachel.halford@hepctrust.org.uk

Thank you for taking the time to read and consider this paper. When it comes to infected blood compensation, the contributors assert that by working together respectfully and sharing ideas in good faith to achieve the best thinking, there will surely be opportunities to increasingly move towards Getting It Right.