



# **Tainted Blood Response to the Infected Blood Compensation Scheme:**

The community has, yet again, been let down

September 2024

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## **Introduction**

### **What is this document for?**

This document is the result of scrutinising the new Regulations and accompanying documentation on the Infected Blood Compensation Scheme, laid and released on 23<sup>rd</sup> August 2024.

Tainted Blood has identified a number of questions arising, and criticisms due, both to the scheme itself and to the way it has been communicated.

We present these here.

## **Onus on victims**

### **No help available for victims...**

The first issue that we feel needs to be raised is this:

To this point, and with no clear upcoming date that this will change, victims have been left to attempt to decipher information coming from the Government by themselves. There has been no clarification about if or when there will be provision of legal advice to potential claimants, nor has there been any word on an advocacy service to help people with their claims. This is having a hugely detrimental effect on the community, with many left in limbo, unsure if they have eligible claims, how much is likely to be offered, and therefore how to plan for any kind of future. Those very ill are worried about whether they will see compensation, or if it will arrive too late, and estate representatives are left to guess about the documentation they will need in order to bring a claim, and whether or not they can afford it.

### **...while the Government gets all it needs**

Whilst the government enjoys full legal expertise in developing the compensation scheme, it is left to victims, in particular campaign groups and victim representatives, to scrutinise and push back against any concerning aspects of the scheme, without the benefit of legal assistance or representation. We are the harmed. To place this onus on us, without any kind of assistance, is to further exacerbate the harm suffered.

We currently have no indication whether IBCA caseworkers or assessors will have the appropriate competency to understand and decipher medical records in order to be able to decide levels of awards that are dependent on complex medical information. Advocacy and legal advice is essential to give victims any kind of trust in the system.

### **Burden of proof once again on the victims**

The compensation scheme's Statutory Instrument clearly states that the burden of proof will be on the applicant. This goes against the recommendations of both Sir Brian Langstaff and Sir Robert Francis.

## **Date of infection**

### **How will first infection be determined where data is not available?**

In many cases, the date of infection will not be known for certain, if at all. Where this is the case, which date will the IBCA use as the date of infection? Will it be from the first known

treatment for people with bleeding disorders, or the first known blood transfusion for whole blood recipients? Will it be from the first positive test result, including prototype tests?

### **Ambiguity for co-infected claimants**

Where there is a co-infection, which virus will be used for the first date of infection? In particular, for those with HIV/HCV co-infection, it will be difficult to determine the date of infection with Hep C and/or B, although it's probable that this will be BEFORE infection with HIV. Will the date of first treatment apply here, to reflect the full number of years infected?

It appears from the Statutory Instrument that HIV is the "tariff trigger" which sets a co-infection claim in motion, however if an applicant was infected with a Hepatitis virus prior to this, that period of infection must also be taken into account.

## **Supplementary route**

### **Heads of loss limited to care and financial award**

We are concerned that there is no supplementary route for the Autonomy, Social Impact and Injury awards. These cannot be truly accounted for in many cases through the Core route or IBSS route. It is imperative that where extra harm has been experienced in these areas, there is recourse to claim enhanced awards via a supplementary route.

### **Limitation on types of financial loss in supplementary route**

In terms of financial losses, will applicants through the supplementary route be able to claim for losses other than earnings? In many cases, huge additional expenses have been thrust upon people's lives which are demonstrable and should be accounted for. Loss of earnings is too narrow to truly account for financial loss.

It is unclear whether any supplementary financial loss route is open to estates.

It is unclear whether there will be a route for those who were infected as children, and who (by the effects of their infections) will have missed out on education and opportunity to become higher earners, to claim for loss of higher earnings, and how this might be calculated.

It is unclear what any cap on the possible claim for financial losses will be. This seems important to know, along with the reasoning behind it.

## **Care costs for the bereaved and estates**

### **Carers have greater losses than the values given**

The care costs applied do not take into account the losses of those who provided care. In many cases, carers and the bereaved will have been forced to give up higher paid work, relocate, and make many sacrifices in order to care for their loved ones. Applying a simple care award, even before a 25% discount, takes none of these factors into account. This is particularly relevant to bereaved partners, who will have lost not only their deceased partner's income, but often their own as well, along with pensions, and with additional expenses incurred in the process of caring for, and coping with, the impact of the injury and death of their loved one.

## **Confusion over past care calculations**

There is confusion over how the past care award is intended to be calculated. The statutory instrument appears to be in conflict with the explanatory memorandum (at 5.8.14) which is counterintuitive and leaves the regulations open to misinterpretation. The memorandum states: "...compensation is calculated by *"working back" from a person's year of death to ensure that expensive end-of-life care is always compensated for*", yet the statutory instrument clauses do not state that past care calculations are meant to run in retrograde from point of death. We contend that "end of life" care is unlikely to be in the 'first 6 months of infection' in most cases. Therefore this new law is incorrect.

## **Individual assessment**

### **There for Horizon, but not for us?**

We note that in the case of the Post Office/Horizon Scandal, claimants may choose to have their cases individually assessed. We believe that this should be open to victims of the Infected Blood Scandal as well. By not having this option available for those who believe that the tariff route does not fit their circumstances, we believe that this is unfair and discriminatory.

## **Hepatitis C awards**

### **Some compensation, but only at death's door**

It appears that the highest award to those infected with Hepatitis C or HCV/HBV co-infection is only available at the point of near death of the applicant (and in the case of HBV level 5, after death). This cannot be viewed as true compensation. For an applicant to be able to be brought up to a point where they would have been, had their infections not taken place, they must have the time to experience that quality of life. Compensating them on the cusp of the end of their life does not accomplish this and in order to be fair, must be earlier.

### **Extra Hepatic Manifestations, mental health and the Special Category Mechanism**

There is a disturbing lack of clarity about how EHMs and mental health issues will be compensated for, in the same vein that the SCM accommodated these extra needs using the SCM.

### **What level was my relative's Hep C infection?**

Where a person has died before their Hepatitis C diagnosis was made, at what level will their infection be graded? This is particularly concerning where a person died from the effects of HIV, without any acknowledgement of a second or third infection which may have contributed to their death.

## **Applicable dates and points of legality**

### **Making it official**

At what point in a person's claim is compensation legally owed to them? Is it from: the point of infection; the point of application to the IBCA; the point at which the legal nature of the Infected Blood Support Schemes changed from ex-gratia to compensation; the point at



which an interim payment was received; the point at which a claim is approved; or something else?

### **Discrepancy in affording compensation to estates of the affected**

In the case of affected people's claims: within the first Interim payment phase, where a bereaved partner died before payment was made, that payment was made to their estate. However, it seems that in the main compensation scheme, an incomplete claim for an affected person dies with them. This is inconsistent and unfair. The main compensation scheme must follow the same principle as the Interim payment for affected people's claims where that person dies, and make the payment to their estate.

In law, when a person dies, their estate must account for monies owed both by and to the deceased. By removing an affected person's claim upon their death, we contend that the law is not being followed and is inconsistent with your own past practice.

## **Application process**

### **Help with what to do next**

There is a great deal of concern due to the lack of information on what will be needed to make a claim. For example, in estate claims, if documentation such as letters of probate or administration are required, this can be a lengthy and expensive process. What assistance will be offered to expedite these, and how will the costs be covered?

In claims for those infected and affected, what evidence will need to be presented, and how will people go about collecting that evidence, some of which will take time and be challenging to obtain?

In general, the lack of information about "what to do next" is causing distress, and must be rectified as quickly as possible.

## **Tax liability and means testing exemptions**

### **What taxes are payments exempt from, and how far removed?**

In previous settlements (MSPT payments, for example) it has been policy that any monies derived from return on investment made using the capital sum would be exempt from Income Tax and Capital Gains Tax. Will this be the case for compensation payments as well? As claimants may be giving up Support Scheme payments in favour of a lump sum (which may be for many reasons, not least to close the door on any continuing relationship with the IBSS entities) then they should be entitled to make that lump sum work for them without being penalised with taxes.

### **Care charges**

Is fresh legislation (or amendments to the Care Act 2014) needed to exempt the compensation (including for the regular support payments) from both residential and domiciliary care charges?

## **The IBSS route after death**

### **Future financial losses**

If the infected decide to take their Future Financial Losses periodically by way of the regular support payment, in the event of their death, would the surviving partner have the option to continue to receive it? Would they be given an alternative option to be paid any outstanding amount up to the full FFL calculation in a lump sum, or would that be paid to the estate?

Currently under the IBSS entities, upon the death of an infected person their bereaved partner receives a support payment at the level of 75%. Will this continue in the compensation scheme? If this is instead passed on to the estate payments, does this not discriminate between two groups of bereaved partners dependent upon when their loved one died in relation to the introduction of the compensation scheme?

### **Loss of other support scheme benefits**

The existing support schemes provide grants and payments as well as the regular payments. For example, the dependent children payments, and grants for disability adaptations and equipment. No information has been provided to advise what will happen to these.

## **Timeframes**

### **When will things begin?**

There are currently no timescales referring to when first applications (from each category of applicant) will be accepted, how long an application is likely to take, and when after approval payment will be made. These are essential components of any Regulation, and to omit them is an extreme oversight.

## **The affected community**

### **Made to wait again, but for what?**

We understand that the affected community is to be made to wait for further regulations which will arrive "at some point". Until then, we only have previous summary documentation to refer to when, inevitably, we are asked what compensation will mean for those affected. The figures for this section of the community are a gross underestimation of the amount of suffering and loss that people have experienced. They must be afforded a supplementary route to enable them to achieve any kind of justice.

## **Summary**

### **The community has, yet again, been let down**

It needs to be acknowledged that, once again, the Infected Blood Community feels that the state has failed them. Since the release of these regulations and the accompanying documentation, many, many people have experienced hugely deleterious mood swings and been tipped into further or increased states of depression and anxiety.

What was expected to be a process of illumination, clarity in navigating a way through the legislation has instead resulted in expressions of feelings of being massively let down and utterly confused. Tainted Blood has seen this even within its own steering group. When people expect officials to hold their hand and lead them through such a complex framework, but instead feel dismissed and left with nowhere to turn except to other victims, there's something wholly wrong.