

**Danielle Holliday**

**From:** GRO-B <GRO-B@GRO-B>  
**Sent:** 22 April 2025 11:26  
**To:** Katherine Cusack; Danielle Holliday  
**Subject:** Fwd: James Quinault Meeting Readout and Unethical Research Award Update  
**Attachments:** Update on Unethical Research Award.docx.pdf; Meeting with James Quinault DG-Readout .pdf

----- Original Message -----

**From:** ibiresponse@cabinetoffice.gov.uk  
**To:** GRO-B @ GRO-B GRO-B GRO-B GRO-C  
**Sent:** Wednesday, January 29th 2025, 12:21 PM  
**Subject:** James Quinault Meeting Readout and Unethical Research Award Update

Dear Tainted Blood Widows,

We are writing to you to share some information and documents following James Quinault's engagement meetings.

**Please see attached a readout of the engagement meetings.**

In the meeting, James updated you on the expanded scope for the supplementary award for victims of unethical research, and explained that his verbal update would be followed up with the details in writing. **Please see attached an updated factsheet on the award.** If your submission did not result in a change to the eligibility criteria, we have also set out below why this is the case.

In December, the Cabinet Office carried out a written engagement exercise with key representatives and organisations in the infected blood community to determine whether the eligibility criteria for the supplementary award should be expanded beyond the proposed date range and list of centres.

For those of you who responded to this (and we understand the various reasons why some of you chose not to), we would like to thank you for taking the time to respond, providing

supporting information, and in some instances detailing personal stories, which we know can be difficult to reshare.

For those of you who responded, we would like to share with you whether your submission has resulted in changes to the policy, and the reasoning if not. While some submissions were accepted, in the case of others which were not accepted, the two most common reasons were that:

1. Sir Robert Francis recommended that this award recognise the harm done to those who were victims of unethical research projects. Therefore, any submissions we received which highlighted treatment practices or clinical policy did not result in a change to the eligibility criteria. We recognise that many people may have been subject to treatment that did not meet proper ethical standards and the core Autonomy award has been designed to recognise this violation of people's personal autonomy.
1. To ensure that the award covers all unethical research projects as defined by the Inquiry, the Government intends for the eligibility criteria to be based on evidence in the Inquiry's report. Specifically, this means where the Inquiry's report references specific protocols, papers, studies, or other written evidence. Some of the evidence we received were individuals' personal stories, medical records, or non-written forms of evidence. This meant that the submission did not result in a change to the eligibility criteria.

In response to your specific submission, the issue that you have raised around research carried out post-mortem is out of scope for this award. Whilst understandably distressing, these concerns do not fall within the scope of this additional award for unethical research projects and have not been highlighted as such by the Inquiry's report.

The situation of tissue samples being taken during a liver transplant is out of scope for this award, as it is about practice that may not have been in line with proper ethical standards, and not unethical research.

There is also no evidence relating to Harewood School in Coventry in the Inquiry's report, and the Government intends for this award to be wholly based on evidence found in the Inquiry's report.

Once again, thank you for your continued engagement with the Cabinet Office.

Kind regards,

Hannah

## **INFECTED BLOOD COMPENSATION SCHEME: MEETINGS WITH COMMUNITY REPRESENTATIVE GROUPS, 17-22 JANUARY 2025**

Update Provided by James Quinault, Director-General at the Cabinet Office

### **Supplementary award for victims of unethical research projects**

Following the written engagement exercise with key representatives in the community in December, the Government has decided to expand the eligibility criteria for the supplementary award for victims of unethical research projects. This means that the position on the eligibility criteria is now that:

- The date range of 1974-1984 will remain unchanged.
- A further four locations have been added. These are the St. Thomas' Haemophilia Centre, Cardiff Haemophilia Centre, Manchester Haemophilia Centre, and Sheffield Haemophilia Centre.
- The eligibility criteria will also include any participation in Dr Craske's studies over the date range.

A factsheet (updated to take into account the position set out above) has been annexed to this readout, with full information on the award and the eligibility criteria. Those who submitted responses to the written engagement exercise will receive a brief explanation of the reasoning, where elements of their submission have not resulted in a change to the eligibility criteria.

### **Interim payments to estates**

Since applications opened in October, 236 payments have been made to date (accurate as of 17 January 2025). The Cabinet Office is grateful for the input of key representatives in the infected blood community on the chains of representations issue.

The Cabinet Office has worked with HMRC and the Probate Services across the UK to resolve issues applicants reported with 'chains of representation'. Our gov.uk pages have been updated to set out what applicants need to do to make an application with a chain of representation. The first cohort of those applying with chains of representation were paid in January.

We value your feedback on the guidance and products available to support interim payment applications, so that we can work to ensure the process for claiming an interim payment is as smooth as possible.

### Infected Blood Compensation Scheme: comments from community group representatives

#### **Regulations**

- Many attendees asked about the timelines for the second set of regulations. James confirmed that the Government intends to lay the regulations in the coming weeks, although this is not guaranteed as it is subject to Parliament. Once the regulations are laid, they are then subject to Parliamentary scrutiny, meaning the Government



cannot provide a firm date for when they will be approved and come into law at this stage but the Government hopes this will be by the end of March.

#### **Supplementary route**

- The supplementary route will be established through the upcoming regulations.
- **Process of applying for the supplementary route:** Representatives raised concerns about whether applying for the supplementary route would delay an applicant's core compensation payment. James confirmed that those who choose to apply under the supplementary route will not have their core route payment delayed. The Infected Blood Compensation Authority (IBCA) will communicate how those who already have started applications for the core route, or who will have done by the time the second regulations come into force, are enrolled onto the supplementary route should they wish.
- **Cap on the supplementary route:** Representatives raised that many in the community would like clarity on what the cap on the supplementary route will be, with particular regard to the evidence-led route for financial loss. James confirmed that there will be a cap, which will be set out in the upcoming second set of regulations. The proposed annual cap for financial loss payments under the evidence-led route will be set at the 90th percentile of UK full time earnings, using 2023 data.
- **Supplementary route for the affected:** Some representatives felt that the Supplementary route should be extended across all heads of loss for all affected people, in order fully to take account of the full range of people's experiences. James confirmed that the Government does not intend to set up a supplementary route for affected people, beyond the option to claim dependency payments for eligible affected people who do not currently receive one through the core route.
- **Special Category Mechanism (SCM):** The list of eligible severe health conditions has been developed following advice from the Infected Blood Response Expert Group. The health conditions included are those that have clear clinical markers for which applicants will be able to provide specific evidence. The Scheme will therefore have different thresholds and eligibility requirements to the Infected Blood Support Schemes for the Severe Health Condition awards.
  - The eligibility criteria that the Scheme uses for the Severe Health Condition Award will not change the value of regular support scheme payments an IBSS beneficiary will continue to receive as part of their compensation package, if that is the option they choose. This will mean that IBSS beneficiaries will continue to receive 'Special Category Mechanism' (or equivalent IBSS category) payments without providing further evidence regardless of Severe Health Condition Award eligibility.
  - However, this does mean that all applicants (regardless of IBSS eligibility) will need to show IBCA that they have one of the qualifying listed health conditions to be eligible for a Severe Health Condition Award through the Scheme's own supplementary route. Specifically, applicants will need to provide medical evidence of their specific health conditions. They may also need to provide evidence that the health impact or condition stopped them from working, and/or assessment of their care needs, to be eligible for supplementary care and financial loss awards.

### **Infected Blood Support Schemes (IBSS) transition**

- **Bereaved partners:** Many asked about the status of those who may become widows or widowers after 31 March 2025, when the IBSS is adopted under the Scheme. James clarified that bereaved partners who are registered with the IBSS before this date will continue to receive 75% of their partner's IBSS entitlement, for life. Those who become widows or widowers after this date will not receive their partner's entitlement, as bereaved partners will be able to apply to IBCA for compensation as an affected person and, if they choose to do so, can receive their compensation as periodic payments. Their partner's estate will also be entitled to compensation.
- **Eligibility for the IBSS:** Concerns were raised about people infected with Hepatitis B, and those who received infected blood or blood products after September 1991, not being eligible for IBSS. A specific question was whether people in these circumstances will receive backdated support payments as part of their overall compensation package. People in this situation will not receive backdated support payments but individuals who are or were infected with a chronic case of Hepatitis B are eligible for compensation under the Infected Blood Compensation Scheme and this includes compensation for past financial loss and care costs. Those who were infected with an acute case of Hepatitis B and died as a result of the Hepatitis B infection during the acute period, are also eligible for compensation under the Scheme. Those infected after the dates in the regulations will not be excluded from the Scheme, if they are able to provide evidence that they received infected blood or blood products.

### **Funding for charities**

- Many raised concerns that Recommendation 10 in the Inquiry's final report, on funding for charities to support claimants, has been accepted in principle by the Government, but not yet delivered on, and that charities are struggling to cope with demand from the community. Ministers are considering how to deliver on this recommendation.

### **Inheritance Tax**

- Any payments made to those eligible under the scheme will be exempt from income tax, capital gains tax and inheritance tax, and disregarded from means tested benefit assessments. Many raised concerns about these exemptions (particularly the inheritance tax exemption), and said that it should cover both the estate of the compensation recipient and the beneficiaries of that estate. This would provide reassurance to those whose beneficiaries are already later in their lives. James explained that the position on inheritance tax exemptions for this compensation Scheme is consistent with the Government's wider policy on tax exemptions.

### **Interest**

- IBCA has begun making payments to infected people and will scale up payments over the coming months. Concerns were raised that those who receive their compensation payments later should receive a sum that takes into account the interest they would have made on that sum, were they awarded it earlier by IBCA.
- IBCA will offer a simple and straightforward scheme that means they can pay compensation as quickly as possible, whilst treating every eligible person with respect and dignity. Calculating individual compensation payments in a way that

accounts for possible interest earned prior to the point of award would be disproportionately complex.

- For those who choose to receive their compensation as periodical payments rather than as a lump sum, the Scheme will index all future periodical payments to the Consumer Price Index (CPI).

#### **Severity bandings for Hepatitis C**

- Concerns were raised during the meetings about the inclusion of multiple severity bandings for the Hepatitis C infection under the Scheme, particularly in comparison to the single severity banding for a HIV infection. Representatives of Hepatitis C victims felt that the multiple severity bandings undermined the experiences of those infected with Hepatitis C, and did not accurately reflect the impact of the infection on people's health and on mortality rates for this cohort. James explained the rationale for the proposed bandings set out in the Expert Group's recommendations to Government.

#### **Abusive Family Members**

- The point was raised that individuals - for example, partners - who had been abusive towards an infected person should not be eligible for awards as affected people. It was suggested that the infected person should have to approve the affected person's application. A request was also made that, in the case of a divorce, compensation payments should be ringfenced when marital assets are divided.
- James said that the Government strongly agreed that it was unfair that persons who had been abusive towards an infected person should share in compensation, but had not so far been able to find a solution to this that was workable within the terms of the scheme and avoided perverse consequences.

#### **Supplementary award for victims of unethical research:**

- James provided an update on the eligibility criteria for this award, based on the written engagement exercise carried out in December. The new position is outlined in the first section of this readout.
- Some representatives reiterated their position that certain hospitals should be included, particularly Belfast Haemophilia Centre and Great Ormond Street Hospital. Some representatives also felt that pharmaceutical companies should bear the cost of this award, and that the awards relating to unethical research should be uplifted.
- James explained that some submissions did not result in a change to the eligibility criteria because they discussed unethical treatment or practice, rather than unethical research, or there was not enough evidence in the Inquiry to support that unethical research took place at a specified location.
- An updated factsheet, and written explanation as to why some submissions did not result in a change to the eligibility criteria, has been shared alongside this readout.



### **Dependency payments**

- A query was raised regarding the value of dependency payments made under the scheme and how this was calculated.
- It was explained that the numbers are derived by taking the maximum value of a living infected person's financial loss award (£29,657) and reducing it by 25%, to account for the amount of money that a person could be expected to spend on themselves.
- For dependents, a value of 75% of that figure is awarded to any partner, and 25% to any children. These values do not change to reflect how many dependents there are. Where there is a partner and no children the partner would still receive the 75% figure and correspondingly if there were multiple children they would each still receive the 25% figure. As such, it is possible for the total dependency paid on behalf of an infected person to be greater than 100% of what the infected person's financial loss award for a year would be (for example if the infected person had a partner and three or more children).
- This differs from the courts, where the court would determine an appropriate value and divide it between any dependents - meaning that in the case of multiple dependents each would receive a reduced share of the compensation.
- It was expressed that this is unfair where there is only one dependent, as they would not receive the full value that they may expect to receive in the courts.
- It was confirmed that this is a consequence of the scheme design, under which no affected person's award is dependent on another person's award. The alternative approach (to, like the courts, generate an award which is divided evenly among all dependents) would go against this principle.

### **Overpayments**

- It was noted that IBCA has the power to recover overpayments - which covers overpayments made both because of fraud and because of error on the part of either a claimant or IBCA. It was requested that either IBCA should not be able to recover overpayments that occur because of its own error, or that there should be a time limit on this power being used in order to give people certainty.
- James explained that the recovery power is needed in order to make sure that public money is properly used and that, where a mistake is made, taxpayer money is recoverable.
- However, he acknowledged that people deserve certainty that overpayments made because of an honest mistake would not be recovered after a certain amount of time.
- Cabinet Office will approach IBCA about this matter and suggest they consider developing and publishing a policy regarding their use of the power to recover overpayments, setting a time limit on its use in situations where there has been no dishonesty.

### Infected Blood Compensation Authority

### **Legal support for applicants to the Scheme**

- **Provision of legal support:** Some queried whether the Cabinet Office is responsible for instructing and funding IBCA's provision of legal support for applicants. It was confirmed that the Cabinet Office has instructed IBCA to provide legal assistance,



and the IBCA are in the process of designing and procuring legal support for claimants beyond the current cohort of claimants.

- **Level of legal support:** Some representatives proposed that support should be available to applicants not just at the point they need to choose whether to accept their compensation offer but throughout the claim process leading to better results and fewer instances of reviews or appeals being needed. James noted that the level of legal support available is a decision for IBCA, and that they are in the process of considering the procurement of this.
- **Use of funding by legal firms:** Many raised that they were concerned about legal firms being instructed to not criticise the IBCA or the Cabinet Office, once they agree to provide legal support to applicants. James said that he had spoken to IBCA and that this was not the intent of the clause - legal firms who come to an agreement with IBCA will not have to avoid criticising either organisation, but simply that the funding they receive from the IBCA should only be used to support applicants, and not for any other purpose.

#### **Timescales for payments**

- Many raised concerns about the timescales for payments, with particular reference to how fast affected people will be able to apply once the second set of regulations are laid.
- James reiterated that IBCA intends to scale up significantly from April onwards starting with applications for living infected people.
- James noted the Government's commitment that payments to the affected would begin this year.

#### **Compensation calculator**

- Many were clear that a publicly available calculator is essential to help people understand how much compensation they are due and to plan their finances.
- James noted that IBCA plan to have a compensation calculator for infected people available by March. This first iteration of the calculator will only cover the core route.