Infected Blood
Compensation Authority

Community Feedback Themes

Communications and Engagement

13/01/2026

This document summarises concerns and issues raised with IBCA by the infected and affected community and stakeholders between October and December 2025. It is not intended to represent the full range of long-standing concerns about the infected blood compensation scheme. We know there are many unresolved concerns about the scheme and continue to share these with Cabinet Office.

The themes shared in this document have been compiled following analysis of IBCA's social media channels, conversations with community representatives and individuals, direct feedback and information from community events.

Themes we have heard and are responding to are outlined below.

1. Speed, timelines, and urgency of progress

- There is continued discussion and frustration regarding the **pace of the scheme** and perceived delays in opening the claim service to other groups of people.
- Specific criticism includes remarks on **3,500 people paid in 18 months.** People said that they simply want to finish the compensation process as soon as possible for their own peace of mind and closure.
- There is an emphasis on the **urgency of progress**, particularly concerning people sadly nearing the end of their life.
- People have criticised the wording around **when claims will begin** for certain groups as 'open-ended'.
- Concern that **prioritising those who participated in previous engagement sessions** might unintentionally exclude others and slow down claims.
- People are **anxious about exactly when payments will start** and when specific groups can begin their claims.
- Questions were raised about whether **IBCA can pay into bank accounts held abroad** or if that slows things down.

In response:

- Our approach is to start with small numbers, learning as we go so we can increase to bigger numbers as soon as possible. We know this can feel frustrating, but it does mean we have been able to start payments much quicker than if we had built the system fully before opening to claims.
- IBCA was established in mid 2024, gained the legal power to pay compensation in August 2024, brought in the first claims in November 2024, and made the first payments by December 2024. By July 2025, we had paid over £600m in compensation, and by September 2025, we had contacted all living infected people registered with support schemes. By the end of 2025, we had contacted over 3,614 people to start claims, with more than £2 billion made in offers and more than £1.5 billion paid in compensation.
- People have fought for decades for compensation and we understand the frustration of not being able to start all claims straight away. We have now opened to more groups and will increase the number of claims this year.
- At this stage, we can't confirm exactly when all claims will start, but we will keep you updated as soon as we can in our community update emails.
- To address concerns about those participating in engagement sessions being prioritised, we published an update explaining that these people will not start their claims sooner than they otherwise would have, in the interest of fairness.
- We have asked people who are sadly nearing the end of their life to come forward so we can prioritise their claim.
- On processing claims as soon as possible, we're working with other organisations, such as the NHS, where we don't yet have the right information or evidence. This helps us access everything we need for someone to make their claim.
- Information about international payments will be included in an upcoming community update.

2. Compensation disparities and policy concerns

Many people, particularly haemophiliacs infected withHepatitis C (HCV), continue to raise concerns about policy proposals outlined in the government's public consultation document, including:

- Strong criticism of the proposed **£10,000 compensation award for unethical research** describing it as 'unacceptable & deeply offensive'.
- Mono-infected haemophiliacs with HCV/Hepatitis C feel **marginalised and ignored**, specifically regarding the failure to recognise their **lost education and career prospects**.

- People have expressed concern about the **disparities in compensation amounts** when compared to high-profile settlements in other compensation schemes, such as that arising from the Post Office Horizon scandal.
- People have asked for more information about how the **supplementary route** will operate.

In response:

- We have shared the strong objections we are hearing about compensation disparities and policy concerns with Cabinet Office. They have asked that these are also raised by community members as part of the public consultation exercise.

3. Policy and prioritisation of claim groups

- We regularly hold **community driven development (CDD) sessions** where community representatives can come and talk about how we plan and deliver our claim service. We've been asked to record and document these sessions.
- There is some confusion and concern that **representatives of deceased infected people might not be paid before other groups**, such as affected families who have already claimed through a support scheme. Some people noted that this prioritisation 'fundamentally undermines the moral imperative to compensate all primary victims first'.
- Concerns raised that the current criteria for claim prioritisation defines 'severity' too narrowly and **does not account for mental health**.
- **People representing the deceased** have told us they feel their situations are fundamentally different from living infected people and require a more tailored understanding.
- There is some confusion about **who is currently eligible to register their intent to claim.**
- People **worry that accepting an offer now might prevent them from receiving more if their health circumstances change.**

In response:

- We publish summaries of our community driven development sessions on our website.
- We are following the Inquiry's recommendation to process claims for all groups in parallel, prioritising those who are elderly or sadly nearing the end of their lives. When you register, we'll ask you about any circumstances that may mean your claim should be prioritised. We will continue to update regularly on claim progress, including publishing fortnightly figures on how many are being brought in, offered and paid.
- We continue to raise your concerns about policy and regulations with Cabinet Office.

- We’ve shared more information on social media and updated our website to be clear on who can register their intent to claim compensation. Anyone who intends to make a claim should register now.
- If your circumstances change, please let us know straight away. If any changes in legal regulations mean you should be paid more compensation than you’ve already received, we will contact you.

4. Documentation and probate difficulties

Difficulties and uncertainty surrounding documentation requirements, particularly probate for estate claims, remain key themes:

- Widows/widowers are experiencing **difficulty in getting probate documents certified**. We heard concerns about probate requirements where multiple family members have evidence but lack formal probate documentation.
- People would like to know **exactly what documentation** is required to show infection and relationship links. Not knowing is causing ‘great mental fatigue’ within the community.
- Attendees at recent events questioned why those who have already received interim payments must do **identify checks (ID verification)** again.
- People are very worried about the **burden of proof** when medical records are inaccurate or have been destroyed.
- The **interim estates process** has been described as highly stressful. People applying have described not receiving correspondence in a timely way, being given wrong payment dates and being spoken to in an unhelpful way. There are also outstanding questions about inheritance tax.

In response:

- We have shared updated probate guidance (this is the legal process of proving a will's validity and administering a deceased person's estate). We have also shared information to encourage people to get probate (or equivalent legal paperwork) early, as claims for a deceased infected person can’t start without it.
- We have passed the concerns regarding the Infected Blood Interim Estates Payment Scheme (IBIEPS) process to the Cabinet Office.
- IBCA published a dedicated 'Documents you might need' page on the IBCA website. Including:
  - Identity verification documents
  - Medical records
  - Employment records
  - Details about care received.
- We ask people to verify their identity so we can make sure the right person is claiming, and protect everyone from fraud.

- IBCA does not require personal representatives to get probate documents countersigned. We are able to check and validate probate documents directly against the national government database.
- We will always try to help people making a claim if their documents have been lost or damaged, and we've explained this further on our website (https://ibca.org.uk/how-scheme-will-work/documents-you-might-need).

5. Trust and transparency

- We heard some **concern around IBCA and Cabinet Office motives**, particularly around who is involved in community engagement work.
- Concerns were raised about the need for greater **Cabinet Office transparency**, including a formal request for IBCA to log all questions passed to the Cabinet Office and their replies.
- Some community members expressed **privacy fears**, leading to discussion about withdrawing statements they had made to the Infected Blood Inquiry.
- Concerns were expressed that the **Hepatitis B community felt they had not been listened to.**
- At the ‘Big Together’ in Northampton, 55.5% of surveyed participants felt ‘completely’ or ‘very’ reassured that IBCA is creating an effective service. More than 70% of attendees felt they were listened to ‘a great deal’ or ‘a lot’. Areas for improvement identified include:
    - Q&A time: More time for questions so that everyone has a chance to speak, particularly when sessions become emotional.
    - Readiness: People would like reassurance that, when it’s time to make their claim, the service is completely ready.
    - Regularity: Providing more frequent and regular updates to keep the community informed.

In response we have:

- Planned drop-in events across the UK in 2026, where people can speak directly to IBCA staff. These events have been planned to give people more time to speak directly to our team and ask questions about the compensation service. In addition, we published a list of the community groups we speak with, and others are always welcome to contact us.
- Worked with community representatives and clinical advisers on Hepatitis B evidence and will share more on this in January.
- Started work on a way for all suggestions to be formally logged, including those shared with Cabinet Office, as recommended by the Infected Blood Inquiry.
- We’ll continue sending our monthly newsletter and keep you updated on our website and social media channels. We will also test that the newsletter works for you, and improve it based on your feedback.