

Briefing for Members of the APPG on Haemophilia and Contaminated Blood for debate on the Infected Blood Inquiry - 22 June 2023

The chairs of the APPG have secured a debate on the Infected Blood Inquiry's recommendations for compensation and redress. The debate is due to take place in Main Chamber of the House of Commons on Thursday 22 June. The debate is the first debate in the main business of the day and is therefore expected to start after the business statement most likely shortly after 11am.

Many people infected and affected by contaminated blood and blood products will be coming to parliament on the day and will be free to meet APPG members before or after the debate.

Background to the debate

On the 5 April 2023 the Infected Blood inquiry published its report on compensation and redress. **The key recommendation is that a compensation scheme should be set up now and begin work this year.** The inquiry chair has said, "The scheme need not await the final report to begin work, since this second interim report fully covers the inquiry's recommendations on financial redress".

The recommendations made to Government include that:

- Sir Robert Francis' recommendations on compensation, with some small amendments, should be implemented immediately
- A single UK-wide compensation scheme should be run by an arms-length body, chaired by a senior judge and accountable to Parliament
- Each affected and infected person should be able to make a claim in their own right
- People should be able to make claims on behalf of the estates of people who have died
- The scheme should avoid adversarial and legalistic standards of proof
- Awards should include: an injury impact award, a social impact award, an autonomy award a care award and a financial loss award
- Bereaved parents and bereaved children should get interim compensation payments now
- The failures of response by the Government should be recognised fully in all awards
- The current annual payments under the support schemes should be guaranteed for life
- A bespoke psychological service should be provided in England (as already exists in other parts of the UK)

Full details are in the full report: <https://www.infectedbloodinquiry.org.uk/sites/default/files/2023-04/Infected%20Blood%20Inquiry%20Second%20Interim%20Report.pdf>

There is no need for the Government to delay in accepting the recommendations from the Inquiry and begin implementing them now. Last summer the Government moved quickly to accept and implement the recommendations in the inquiry's first interim report on compensation. It should now do the same for the full and final recommendations on compensation and redress.

The Arms-Length Body

The Infected Blood Inquiry recommendations provide a clear blue-print for a body to administer the compensation framework, review claims and make payments. The Government should be appointing a chair to lead this body, in consultation with infected and affected people and their representatives.

As soon as it has a chair, the body should start recruiting panels to review applications, build processes for reviewing claims, ensure they are ready to contact eligible people and allow people not covered by the current support schemes to register. They must also ensure active and relevant involvement by infected and affected people in their work and processes. An independent appeals and review process will also need to be created.

The body must be well-resourced with this resource “front-loaded” to deal with the thousands of applications that are likely to be made as soon as it is set up.

Nothing about us without us

The contaminated blood community is a diverse and complex group of individuals with a wide range of experiences and different needs. A one size fits all approach is not appropriate. It is not reasonable for decision makers to expect a unified voice from a community which is so diverse. Expecting that would deny the voice of minority groups.

People infected and affected by contaminated blood products often say that no decision about their future should be taken without their input. Any decision making or consultation with patient groups and campaign groups must respect that diversity. The Government and other bodies should work with patient groups and campaigners but people infected and affected must also be supported and encouraged to speak for themselves.

Further delay and lack of information is having a serious impact on people’s mental health and further undermining trust in a Government that said it would pay compensation if the inquiry recommended it. These recommendations have now been made so the Government need to end the uncertainty people are facing. Further, more than 500 people affected by the scandal are estimated to have died since the Inquiry began, in addition to the thousands we have already lost. **There is no time to waste in delivering compensation to surviving victims and others affected.**

Questions for the Government include:

- How advanced is work towards meeting the recommendations in the report? When will they accept the recommendations in full?
- Have they begun approaching people to chair the compensation body? How will they involve people from the affected community in this process?
- It is vital that the Government involve people who were infected with contaminated blood and blood products in their work. Infrequent, over-subscribed meeting with Government is not an effective way to understand people’s needs. Can relevant civil servants meet more often with smaller groups of people and with representative groups and charities as they develop this policy?
- Can they give people more detail and more frequent updates on the work taking place? This is causing a lot of apprehension among the affected community as they do not know what is being done and they do not feel involved in the process and the decisions being made about their future.
- Does the Cabinet Office have sufficient capacity for this work and have they appointed a new senior civil servant to lead the team working on this?
- How often is the cross-departmental working group meeting? What updates can they provide on this work?

- Given the urgency of implementing these recommendations will the Government commit to have a compensation scheme in place by the end of the year, as the recommendations set out?
- Last year the Government moved quickly to pay interim compensation to surviving infected people as recommended in the inquiry's first interim report. How soon will they be able to make these interim payments to bereaved parents and children?
- Does the Government agree with the inquiry's conclusions that "wrongs were done at individual, collective and systemic levels" and does the Government accept responsibility for its role in those wrongs?
- Many people infected and affected by contaminated blood and blood products are currently confused as to what they need to do next. When will the Government be setting up a mechanism for people to register to make a claim for compensation and so they can be updated directly?
- Is the Government considering any awareness raising campaigns among the general public or drives among GPs for the purposes of screening, to ensure that in remaining cases where people may have been historically infected, they can access testing and - if needs be - treatment and compensation?
- People need better psychological support now – by what date will the new bespoke psychological service in England be set up and for how long will this support be offered for?

To spare people more worry and anguish the Government should commit now to implementing the recommendations of the Infected Blood Inquiry in full, so we learn from what happened and people see the justice they deserve.

History

In the 1970s and 1980s around 5,000 people with haemophilia and other bleeding disorders were infected with HIV and hepatitis viruses through the use of contaminated clotting factors. Some of those unintentionally infected their partners, often because they were unaware of their own infection. Since then more than 3,000 people have died and of the 1,250 people infected with HIV less than 250 are still alive.

Also, many people who did not have a bleeding disorder were infected with hepatitis C as a result of blood transfusions during that period. The best estimates we have suggest that around 27,000 were infected with hepatitis C, of whom around 10% were still alive and seeking justice as of 2019.

The Infected Blood Inquiry into the contaminated blood scandal was set up following an announcement by Prime Minister Theresa May in 2017. In a statement to Parliament, Mrs May described the scandal as 'an appalling tragedy which should simply never have happened'.

The inquiry officially got underway on 2 July 2018 and after five years of evidence gathering and analysis is expected to publish its final report in the Autumn.

You can get more detail on the Infected Blood Inquiry and the contaminated blood scandal from the haemophilia society here: <https://haemophilia.org.uk/public-inquiry/the-infected-blood-inquiry/>