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28 May 2025

RE: ADDITIONAL SUBMISSION ARISING FROM TRANCHE 055

It is with disappointment that CBC feel the need to comment on the fact we have been given very little time by the Infected Blood Inquiry to respond to the recently released disclosure to Tranche 055 (IBCA and Government Response on Compensation).

We received an email on Thursday 22 May confirming that we had a deadline of noon on Wednesday 28 May to respond. Given this tranche ran to some 30 documents, some of which were very large and detailed, this has made it incredibly stressful and time-consuming to read, absorb and respond by the deadline, which has meant once again, campaign work eating into our weekend, Bank holiday and family time.

If any organisation understands the pressures that we as a community face, it should be the Infected Blood Inquiry. This tight deadline will effectively mean that most people and campaign groups are not able to respond fully, if at all, by the deadline set.

It is also relevant to note that as the Hepatitis community are being dealt with vastly differently to those with HIV, it is therefore in our interest to do our very best to scrutinise all information put out by the Inquiry. It is not 'job done' for us, we are the ones having to fight on with all the health and psychological impacts we face on a daily basis with only our own resources to rely on.

We detail below our comments on some of the relevant documents:

CABO0000915

1) On page 5, para 7, it says: *I propose to say that the proposed Scheme is subject to validation with representatives of the infected blood community, prior to being established in regulations. The validation will test whether the tariff-based framework of compensation proposed takes proper account of the breadth of cases, and will sense check the Government's proposals on matters such as evidential requirements and support for applicants. Under the terms of the Victims and Prisoners Bill, the regulations to set up the Scheme must be laid within three months of the Bill receiving Royal Assent. Accordingly, the scope and duration of the exercise will necessarily be limited.* I am not aware of any representatives of the Infected Blood Community validating any of this work.

2) On page 6, para 17 it includes the sentences: *There are risks to the successful delivery of the scheme to the timetable applicants will expect. We are mitigating this by designing the scheme to be as simple to run as possible,* The original scheme set up by Government was highly complex and has become even more complex as further iterations of the scheme have developed. The fact remains, Government could not have developed a more complex scheme if they had tried. This is not what the community expected and it is certainly not what Sir Brian Langstaff and Sir Robert Francis recommended. We were failed from the beginning. One of the key reasons for this failure is the fact the Government did not consult with the community before making their own decisions.

CABO0000916

3) On page 20, para 75 it says: *You have requested further advice on options for validating the design of the Scheme with the community following the announcement. It is important that any engagement, regardless of whether this is as part of a formal consultation or not, does not ask for views on matters which are already settled by the Government. This is part of the Government's Consultation Principles and there is a very high risk of successful legal challenge if the Government seeks views on matters where it has no intention of altering its decision. The Government must properly consider the views of those it chooses to consult with in its decision making before the final decision is made.* This paragraph represents one of the clearest examples of Government's determination not to engage with the

community in any meaningful way whatsoever, and particularly where decisions have already been made by Government without our input.

4) On page 22, para 86 it says: ***Since advice was sent to Ministers on 1 May the Expert Group has updated the proposal for HIV and co-infections financial loss formula. Unlike HCV and HBV infections, the Expert Group has linked impact on financial loss for HIV and co-infections of HIV and HCV/HBV to the infected person's diagnosis status as introduction of effective treatment is not considered to have resulted in a significant improvement to the quality of life and work capacity of individuals considering side effects.*** Assuming the experts have said that the introduction of effective treatment for HIV is not considered to have significant improvement to the quality of life and work capacity of individuals considering the side effects, this begs the question, why those that have been on the horrendous treatments for Hepatitis C and continue with serious illness have not been classified the same by the expert group. The fact is, we still do not know what specific discussions took place within the Clinical Expert group and this is yet another reason why we need to see the details of those discussions rather than rely on what the Government say the Experts have said.

CABO0000918

5) On Page 2, para 8 it says: ***There is a risk that accepting recommendation 14 in full will not provide the Government with proper oversight of the potential fiscal spend incurred by the compensation scheme. We recommend that the expert committee is appointed with a chair who provides advice directly to you (MCO) for decision-making purposes, rather than taking independent decisions.*** This paragraph represents clear evidence that Government are more concerned about the cost of the compensation scheme rather than accepting Sir Brian Langstaff's recommendation 14 which would have provided independent oversight.

6) On page 7, Inquiry Recommendation 5: it says ***I recommend that infections eligible for compensation should be classified in the following manner: a) there should be defined categories for each type of eligible infection, and the stages through which it progresses, and for each category defined degrees of severity to which a range of possible awards for the impact of the disease can be applied; b) the stages and degrees of severity for each disease should be defined by an independent clinical expert advisory panel, by reference to***

clinical professional consensus; 94 c) the range of potential awards for the impact should be determined by an independent advisory panel of legal experts, taking account of but not limited by current practice in courts and tribunals across the UK The Government and/or the Clinical Experts have completely failed to apply Inquiry Recommendation 5 across all infections. While those with HIV have a single category, those with Hepatitis are divided into multiple stages and categories. Again, we need to see the detail of the discussion that took place within the Expert Group/s to understand why this has happened.

CABO0000925

7) This 69 page document included minutes of meetings which consisted of the clinical and legal expert groups. However, I was disappointed to read that the minutes were only a summary of the Expert Group's meetings and topics for discussion; there was no detail whatsoever anywhere in the document which included the discussions and debate that took place between the Experts themselves and the Cabinet office. It is also relevant to note that the Cabinet Office themselves have chosen what parts of the discussions should be included and excluded. This does not represent openness and transparency.

Since 20th May 2024, CBC has been submitting multiple FOIs into the Cabinet Office to ask for the release of information which would uncover the discussions between the experts and the Cabinet Office, and importantly, including any agendas set by the Cabinet Office. Following complaints to the Information Commissioners Office (ICO) the Cabinet Office finally provided information relating to our FOI requests however, they used their aged old tactic of only providing a 'summary' response which did not provide the detail we had requested. ***Please see timeline of our FOIs at the bottom of this submission.** There is clearly a pattern developing here as the information provided to the Infected Blood Inquiry once again only provided a 'summary'. This manipulating tactic is allowing the Government to get away with choosing which information they will and will not release which is unacceptable, lacks transparency and fails any reasonable test of candour.

Once we saw this latest tranche of information had been released on the Infected Blood Inquiry website we had hoped it would include the detail of the discussions between the Cabinet Office and their Expert Groups and we were deeply disappointed to see that it did not. CBC has noticed in recent

communications with the Cabinet Office that in order to hide the detail and therefore the truth, the Cabinet Office consistently rely on the release of 'summary' documents only.

This is not acceptable therefore CBC request that the Infected Blood Inquiry writes to the Cabinet Office and compels them to:

- i. Release the details of discussions/debates within the Expert Group/s and include the discussions/debates between the Expert Group/s and the Cabinet Office;
- ii. We need to see specific agendas that have been set for the expert group/s by Government.

We need and deserve to see those discussions/debates in order to understand how the Government has arrived at their decisions. We don't want summaries and we don't want overviews which have been decided by Government, we need to see the un-filleted and un-redacted details.

Having access to the detailed discussions/debates that have taken place will either validate or undermine the Government's position that it was the Experts that made key proposals to divide our community into multiple stages and categories which are now being faced by the Hepatitis community. Government may say that it is not possible to release this level of detail however, as you will see from my first written statement to the Inquiry **WITN2050001** dated 14 August 2020 at paragraph 122, I refer to FOIs I submitted to the Department of Health and Social Care in 2011 which resulted in a detailed response including discussions, letters, emails and reference documents which the Clinical Expert Group used for the Government Review which was published on 10 January 2011.

The Inquiry clearly has the power to compel the Cabinet Office to release this information and this may be the last opportunity we have.

8) As referred to above, it is clear that specific information provided by the Clinical Experts is not known by anyone other than the Cabinet Office. This information is of the highest importance if we are ever going to understand why Government have made the decisions they have. We would like to strongly request that Inquiry call the Clinical Experts to give oral evidence to cover these issues, or at the very least, we request that the Inquiry should

submit questions to the Clinical Experts following the involvement of our solicitors, campaigners and the community.

9) On page 20, under the title **ACTION:-** it says: ***The Stakeholder team would meet with the relevant Expert Group members to further develop their engagement plans, particularly with individuals in the HIV community.*** This represents a clear example of the prioritisation of the HIV community. This example is possibly one of the reasons why the Hepatitis community has been undermined from the beginning.

10) On page 23, under (ii), bullet point 3 it says: ***It was confirmed that all individuals claiming for HIV infection would be categorised as 'severe.*** CBC would like to know which Expert/s arrived at this conclusion and on what grounds? We would also like to know if any of the experts classified liver cirrhosis as 'severe', particularly as there is no medication available for liver cirrhosis and there is a high risk of cancer once someone develops liver cirrhosis, which requires bi-annual liver tests.

11) On page 24, Infected Awards bullet point 3 it says: ***Individuals with HIV would have care requirements for co-morbidities in addition to the direct impact of the disease.*** There has clearly been no comments anywhere within these documents which discuss co-morbidities of having a bleeding disorder which includes associated co-morbidities between having a bleeding disorder and Hepatitis infection.

12) We find it difficult to believe the Clinical Expert group didn't discuss anything to do with the horrendous side effects of interferon and ribavirin treatments, including the long-term effects of these treatments; the extra hepatic manifestations and vCJD. It is hard to believe they didn't discuss the issue of the need for bi-annual testing once liver disease has progressed to liver cirrhosis with all the lifelong worry that entails however, I couldn't find anything to do with these issues within the summary minutes.

It is this lack of detail which leads me to believe that the Cabinet Office have effectively 'cherry-picked' what information they have chosen to release within their summary minutes.

WITN7755009

13) On page 8 para b. it says: ***In current cost modelling we have treated all currently registered SCM individuals on IBSS as receiving Cirrhosis levels of care award and financial loss award. Under the refined health impact group 6 eligibility criteria fewer of the currently registered SCM individuals would be eligible for group 6. This is a net reduction in cost compared to our original cost estimate. We estimate that approximately 835 individuals currently registered as SCM on IBSS apply for compensation. If only half are eligible for the Health Impact route, the overall cost of their entire compensation would be approximately £100 million less than our original estimate.*** This represents yet another blatant example of the Government's interest in undermining the compensation levels for the Hepatitis community in order to save money. There has never been any doubt in our minds that the Government are using the Hepatitis community as financial scapegoats and this example highlights this perfectly.

CABO 0000926; WITN7757014; WITN7757015

The links to the above files could not be found on the Inquiry website and we were unable to read and therefore respond to these documents.

Thank you for taking the time to read this submission.

Kind regards

GRO-C

Glenn Wilkinson

For and on behalf of Contaminated Blood Campaign

***timeline of our FOIs**

FREEDOM OF INFORMATION REQUEST TIMELINE TO AND FROM THE CABINET OFFICE

Glenn Wilkinson 1st set of FOI Requests

FOI sent by G Wilkinson on 24th May 2024
FOI sent by G Wilkinson on 24th May 2024
Acknowledgement received 28th May 2024, merging the 2 separate FOIs into 1 (FOI 2024/07006)
Email received 24th June 2024 delaying their response to 23rd July 2024
Email sent on 10th July 2024 criticising the delay
Response received on 23rd July 2024, stating £600 limit exceeded. Suggested refining the request.

FOI Request Glenn Wilkinson Refined

Refined FOI sent by G Wilkinson on 2nd August 2024
Acknowledgement received from CO 5th August 2024 (FOI 2024/10432)
Reply received 3rd September 2024 stating they were unable to comply with the request as it exceeds a £600 limit
G Wilkinson requested an internal review on 29th September 2024
Acknowledgement received from CO 1st October 2024 (IR 2024/12963)
Internal Review received 26th November 2024, upholding the decision

As I was told my original FOI was too broad it was decided to break the question down into narrower questions and we also decided to have these FOIs sent by 4 different people so the Cabinet Office were unable to link the questions to one individual which could exceed their £600 limit.

FOIs were sent by the following people:

Alison Wilkinson

FOI sent on 2nd October 2024
Acknowledgement received from CO 3rd October 2024 stating their aim to respond by 30th October 2024 (FOI2024/13031)
Email received 30th October 2024 delaying their response to 27 November 2024
Email received 27th November 2024 delaying their response to 30th December 2024
Email received 30th December 2024 delaying their response to 29th January 2025
ICO was contacted to ask about making a complaint regarding these ongoing delays. Was advised to write to the CO advising them of an intention to make a complaint. This was done on 9th January 2025.
A complaint was made to ICO on 9th January 2025

Confirmation email received on 22nd January 2025 (and letter) from the ICO
On the 29th January 2025, the CO responded to the original FOI of 2nd October 2024

Email received on 30th January 2025 from ICO confirming case closed as CO have responded.

Lesley Brownless

FOI sent on 2nd October 2024

Acknowledgement received from CO 3rd October 2024 stating their aim to respond by 30th October 2024 (FOI2024/12999)

Email received 30th October 2024 delaying their response to 27 November 2024

Email received 27th November 2024 delaying their response to 30th December 2024

Email received 30th December 2024 delaying their response to 29th January 2025

ICO was contacted to ask about making a complaint regarding these ongoing delays. Was advised to write to the CO advising them of an intention to make a complaint. This was done on 9th January 2025.

G Wilkinson was authorised by Lesley to take over the complaint.

A complaint was made to ICO on 14th January 2025

Email received on 22nd January 2025 from ICO confirming they have asked the CO to respond.

On the 29th January 2025, the CO responded to the original FOI of 2nd October 2024.

Jackie Britton

FOI sent on 2nd October 2024

Acknowledgement received from CO 3rd October 2024 stating their aim to respond by 30th October 2024

Email received 30th October 2024 delaying their response to 27 November 2024

Email received 27th November 2024 delaying their response to 30th December 2024

Email received 30th December 2024 delaying their response to 29th January 2025

ICO was contacted to ask about making a complaint regarding these ongoing delays. Was advised to write to the CO advising them of an intention to make a complaint. This was done on 14th January 2025.

G Wilkinson was authorised by Jackie to take over the complaint.

A complaint was made to ICO on 15th January 2025

On the 29th January 2025, the CO responded to the original FOI of 2nd October 2024 but they have failed to provide the detail we are looking for.

GRO-A

FOI sent on 3rd October 2024

Acknowledgement received on 4th October 2024 stating their aim was to respond by 31st October 2024

FOI Response received on 31st October 2024