



**SUPPLEMENTARY LETTER OF INSTRUCTION TO HEPATITIS
EXPERT GROUP (PALLIATIVE CARE IN ADVANCED LIVER DISEASE)
December 2021**

Dear Dr Graham Cooke

Re: The Infected Blood Inquiry

1. I am writing on behalf of the Chair to the Infected Blood Inquiry, Sir Brian Langstaff, with instructions for the preparation of a supplementary report by the hepatitis expert group ('the group'), addressing matters of palliative care for people with advanced liver disease. It is anticipated that the matters in this letter will be addressed by you, as convenor of the group, and Dr Hazel Woodland, Dr Ben Hudson, and Dr Fiona Finlay. I have provided copies of this letter to them. If you consider that other members of the group may be able to assist in answering the questions within this letter, please let me know and I can provide copies of the letter to them.
2. The purpose of the report is to provide evidence about matters within the expertise of the group that may assist the Chair in fulfilling the Inquiry's Terms of Reference. I set out in more detail below the topics and questions that the Chair asks you to address at this stage. The report will be provided to the Core

Participants to the Inquiry and will be published on the Inquiry's website.

3. In due course, I may ask the group to undertake further work to assist the Inquiry. This may include answering questions raised by Core Participants, preparing further reports, conducting discussions with or providing opinions to other expert groups instructed by the Inquiry, giving oral evidence at the Inquiry's public hearings, and carrying out other duties appropriate to the role of an expert to the Inquiry as directed by the Chair through me.

Background

4. As you are aware, the Infected Blood Inquiry has been established to examine the circumstances in which people treated by the National Health Service in the United Kingdom were given infected blood and infected blood products. It is an independent public inquiry under the Inquiries Act 2005.
5. The provision of such blood and blood products led directly to people becoming infected with Hepatitis B virus ('HBV'), Hepatitis C virus ('HCV'), Human Immunodeficiency Virus ('HIV') and other diseases. Other people were indirectly infected. People have also been informed that they may be at risk of developing vCJD.

The Inquiry's Terms of Reference require it to consider and report upon a wide range of issues which have been set out in previous letters of instruction and a full version of the Terms of Reference may be found on the Inquiry's website. The website also contains the Inquiry's List of Issues, which provides more detail of the matters that may be explored during the course of the Inquiry. I have sent links to both these documents to the group.

6. The Inquiry must report its findings to the Minister for the Cabinet Office, and make any recommendations, as soon as practicable.

Instructions

7. The Inquiry has received and considered many written witness statements from people who have been infected (or whose partners or family members were infected) with HCV, HBV and/or HIV, many of whom have also been told of exposure to the risk of vCJD. The Inquiry has also heard a substantial amount of oral evidence from such individuals.
8. So as to inform his analysis and consideration of that evidence, the Chair would be assisted at this stage by receiving a report addressing the following topics, insofar as they are within your area of expertise and it is possible to address them on the evidence and data available to you:
 9. Is there a role for palliative care in advanced liver disease, and if so how does it relate to end-of-life care?
 10. What are the hallmarks of effective palliative care for advanced liver disease?
 11. To what extent does palliative care for advanced liver disease (as presently offered by the NHS in the UK) demonstrate these hallmarks? In particular:
 - (a) how (if at all) does palliative care differ from area to area?
 - (b) how, if at all, does it differ depending upon the nature of the hospital concerned (teaching/non-teaching; rural/urban; etc)?
 - (c) in what particular respects is it lacking?
 - (d) by what reasonable means can any shortfall in standard be remedied – and how easy would this be?
 12. Do barriers currently exist to patients accessing advanced palliative care for liver disease, and if so what are they?

13.If there are such barriers, how best can they be overcome?

14.What (if any) improvements have there been since 2000 in

(a) understanding of the role and nature of palliative care in advanced liver disease, and (b) providing it, compared to what happened before then?

15.What would best secure continuing improvement?

16.The Chair is conscious that as members of the group you have great expertise and experience in your respective fields. The topics are intended to provide a focus and structure to your work for the Inquiry. If you feel that the topics could helpfully be rephrased, or if there are matters that you consider should be added or omitted from those set out above, then please provide your suggestions in a letter to me. The Chair will consider any points that you raise and I will respond to you with his decision.

17.The topics are deliberately framed in broad terms. This is intentional, with the aim of allowing the group to approach the matters as you see fit.

18.It is important to note that whilst you can be provided with extracts from both written and oral evidence given by individuals where requested to inform your work, you are not being asked to express an opinion either on the circumstances of any particular individual's experience or on the likelihood of any particular impact being suffered by an individual or indeed a group of individuals.

Further information

19.The manner in which you address the topics set out is a matter for you, as is the way in which you express your conclusions and any qualifications that

accompany them (including qualifications on the confidence or uncertainty that accompany a particular issue or range of issues).

20. The report should make clear if there are any matters on which it is not, or may not be, possible to provide an expert opinion, for example due to the lack of available information. The report should give the reasons for any such limitation.

21. If there is a range of professional opinion on a particular issue covered in the report that must be made clear and the range of opinions summarised. The report should explain why you have reached the particular conclusion that you have.

22. If there is a disagreement among group members about any matter within the report, then this too should be made clear. The report should summarise the range of opinions, attribute them to the relevant group members, and provide the reasons explaining the views expressed.

23. The Inquiry has instructed other expert groups during the course of its work. You may consult freely with members of these other expert groups, as may help you, but should acknowledge in your report what, if any, material assistance their input has given you.

Expertise and Duties of an Expert

24. If having read this letter you or other members of the group feel that you do not have the appropriate experience or expertise then please let me know immediately. You should also notify me if you have any queries or require any further information.

25. As an expert witness, you have a duty to exercise reasonable skill and care in carrying out your instructions and must comply with any relevant professional

code of practice. Your overriding duty is to assist the Inquiry and to provide your unbiased opinion as an independent witness in relation to those matters which are within your expertise.

Format of the Report

26. In preparing your report please make sure that:

- a. It sets out details of the qualifications of all members of the group and their academic and/or professional experience.
- b. It gives details of any literature or other material which you have relied on.
- c. It contains a statement setting out the substance of all facts and instructions which are material to the opinions expressed.
- d. It makes clear which of the facts stated are within your knowledge.
- e. It identifies who carried out any other work used for the report. The report should give the qualifications for the individual and indicate whether their work was carried out under your supervision.
- f. Where there is a range of professional opinion on the matters dealt with in the report, it summarises the range of opinions and gives reasons for the opinion reached.
- g. It contains a summary of your conclusions.
- h. It sets out any qualification to an opinion or conclusion provided.
- i. It contains a statement that each of the group members understands their duty to provide independent evidence and has complied with that duty.

27. The final report must be verified by statements from all contributing group members saying:

"I confirm that in respect of those parts of the report to which I have contributed:

- a. I have made clear which facts and matters referred to in this report are within my knowledge and which are not.*
- b. Those that are within my knowledge I confirm to be true.*
- c. The opinions I have expressed represent my true and complete professional opinions on the matters to which they refer."*

28. You should let me know immediately if at any time after producing your report and before the conclusion of the Inquiry you change your views. It is also important that you notify me promptly if you feel it is necessary to update your report after it has been finalised, for example because new evidence has come to light.

29. The report should be reasonably concise and expressed as far as possible in straightforward language. Where technical or clinical terms are used, and their meaning may not be obvious, please provide a brief explanation as to their meaning.

30. I would be grateful if in general you, Dr Graham Cooke, would undertake to be the point of contact for all correspondence between the group and the Inquiry.

Timetable

31. I would be grateful if you could provide a draft copy of your report by 17 January 2022.

32.I ask for the report to be provided in draft in the first instance so that I can approve its format, check that the formal requirements for an expert report mentioned above are fulfilled correctly and ask for any queries to be addressed before the report is signed.

33.Once the report is finalised, a copy will be disclosed to the Core Participants and will be published on the Inquiry website. It may be that once Core Participants have reviewed this letter of instruction or your report they will identify further issues that I may wish to raise with you.

34.I may also provide you with further instructions at a later date in respect of any other matters on which we seek evidence from the group.

Fees

35.I will correspond with you separately about arrangements for your fees.

Next Steps

36.To progress matters as quickly and efficiently as possible, I would be grateful if you and the other group members can return to me a signed confidentiality undertaking. Once that is received I will contact you to discuss how best to provide access to the evidence that the Inquiry has obtained. I hope you can then begin work on reviewing that material and preparing your report.

37.As I have indicated in this letter, and if you feel that it is appropriate, please write to me if you consider that the questions or topics should be amended or changed.

38.May I thank you and the other group members once again for agreeing in principle to assist the Inquiry. If there is anything that I can do to assist or there are any aspects of these instructions that you would like to clarify then please

do not hesitate to contact me.

Yours sincerely,

A handwritten signature in blue ink that reads "Moore Flannery". The signature is written in a cursive style with a large initial 'M' and a long, sweeping underline.

Moore Flannery ,

Infected Blood Inquiry, Secretariat.