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**LETTER OF INSTRUCTION TO PSYCHOSOCIAL  
EXPERT GROUP  
25.09.2019**

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**Professor Weinman**

Dear Professor Weinman,

**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 report by the group of psychosocial experts ('the group'). You have kindly agreed to convene this group, and to act as a point of contact between the group and the Inquiry. The other members of the group are **Dame Lesley Fallowfield, Dame Theresa Marteau, Dr Veronica Thomas, Sian Edwards and Professor Deborah Christie**. I have provided copies of this letter to them. The group is invited to consider which members are best placed to undertake the work outlined below and to notify the Inquiry accordingly.
  
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. The Chair will ask one or more contributors to the report to speak to its content at the Inquiry's public hearings in late February 2020.

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.
6. The Inquiry's Terms of Reference require it to consider and report upon a wide range of issues. These include:

*"To consider the impact of the infection from blood or blood products on people who were infected ("those infected") and on partners, children, parents, families, carers and others close to them ("those affected"), including:*

*a. the mental, physical, social, work-related and financial effects of:*

*i. being infected with HIV and/or HCV and/or HBV in consequence of infected blood or infected blood products;*  
*ii. the treatment received for those infections;*

*b. the extent to which treatment, medical and dental care for other conditions was compromised by perceived infective status;*

*c. the impact of these infections on partners, children, parents, families, carers and others close to those infected, including the impact on those who suffered bereavement; children who were taken into care; those who were advised to, or did, terminate pregnancies; and those who had to take difficult decisions about whether or not to have children;*

*d. the wider social impact on those infected and affected, including the stigma associated with a diagnosis of HIV and/or HCV and/or HBV.”*

The report, which the group is being asked to produce at this stage, will assist the Chair in considering this part of the Terms of Reference.

7. 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.
8. The Inquiry must report its findings to the Minister for the Cabinet Office, and make any recommendations, as soon as practicable.

## **Instructions**

9. 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. So as to inform his analysis and

consideration of that evidence, the Chair would be assisted at this stage by receiving a report discussing the psychosocial impacts and consequences of infection, both for people infected and for people affected. It is important to note, however, that whilst you will be provided with extracts from both written and oral evidence given by individuals, you are not being asked, in any of the questions below, to express an opinion on the circumstances of any particular individual's experience.

10. The Chair is conscious that as members of the psychosocial group you have great expertise and experience in your respective fields. The topics and questions set out in the paragraphs that follow are intended to provide a focus and structure to your work for the Inquiry. If you feel that the topics or questions could helpfully be rephrased, or if there are matters that you consider should be added or omitted from those set out below, 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.
11. You will of course be aware that many of the incidents contained within the evidence happened years ago. You are, however, being asked to express your opinion on the matters set out below from today's perspective, irrespective of what may have been the practice or known about these matters in previous decades.
12. The topics and questions set out below are deliberately framed in broad terms. This is intentional, with the aim of allowing the group to approach the matters as you see fit.
13. As far as possible, your report should cover the following topics insofar as they are within your areas of expertise and it is possible to address them:
  - 13.1. Psychological impacts of infection on people infected and affected:  
Please explore and discuss the psychological impacts of being infected with HIV, HCV, HBV and/or of being at risk of developing vCJD, by blood or blood products. Please also explore and discuss the psychological

impacts on those affected by the infection of a person close to them. Please consider as part of this topic the psychological impacts and stresses of serious and/or constant ill health (often leading to multiple treatments with severe side effects). You are asked to note that the Inquiry has received evidence from witnesses describing a range of psychological reactions on the part of persons infected and persons affected to the fact of infection with hepatitis and/or HIV and/or to the risk of being infected with vCJD, including anger, depression, PTSD, shame, guilt, fear for oneself and of infecting another person, grief, survivor's guilt, risk taking behaviour, going off the rails, disbelief, shock, social isolation and/or helplessness.

- 13.2. The psychological impact, on people infected and affected, of having to continue to be treated by, or interact with, professionals or medical institutions whom they hold responsible for the original infection and/or the impact of a loss of trust more generally in the medical profession or the NHS. In addition, the impact on those who must continue to receive the same treatment that was itself the cause of their infection. (The Inquiry has, for example heard from witnesses who no longer feel able trust clinicians or NHS bodies but who continue to require treatment for lifelong conditions such as haemophilia or thalassaemia).
- 13.3. Social impacts of infection on people infected and affected: Please explore and discuss the social impacts of being infected with HIV, HCV, HBV and/or of being at risk of developing vCJD, by blood or blood products. Please also explore and discuss the social impacts on those affected by the infection of a person close to them. Please consider as part of this topic the social impacts and stresses of serious and/or constant ill health (often leading to multiple treatments with severe side effects). You are asked to note that the Inquiry has received evidence from witnesses describing a range of adverse social consequences of infection, including relationship or family breakdown; divorce; deciding not to have, or being unable to have, children; reduced ability to care for or interact with one's children; losing friends; social isolation; loss of

employment; limited employment or career opportunities; detrimental impact on education; and financial hardship.

13.4. Psychosocial impact of poor, inadequate and/or insensitive communication of information about testing, diagnosis, infection and treatment: Please explore and discuss the psychosocial impacts of poor, inadequate and/or insensitive communication of information about testing, diagnosis, infection and treatment. In particular please address the following issues:

13.4.1. What is the best way to inform a person that they are infected with a serious disease? Please explain why following best practice in this regard is important and the potential consequences if best practice is not adopted.

13.4.2. What is the best way to inform a person that they have been infected with a serious disease as a result of medical treatment they have received? Please explain why following best practice in this regard is important and the potential consequences if best practice is not adopted.

13.4.3. From a psychosocial perspective, has best practice in terms of communicating with patients changed over the years, and if so, how and why?

13.4.4. The Inquiry has received evidence from a range of witnesses who have described being told of their infection by letter, over the phone, casually or informally in a non-private setting or being told of their infection by someone who has little knowledge of the disease, or being told in an indifferent, unsympathetic or callous way. Could the way in which a person is told of their infection affect the psychological experience of that individual and if so, how and why?

- 13.4.5. The Inquiry has received evidence from a range of witnesses who have described not being told that the treatment which they were being given (whether with blood or blood products) might expose them to a risk of infection and/or who have stated that they did not give informed consent to such treatment. Could a failure to provide sufficient information about risks and/or a failure to obtain informed consent affect the psychological experience of the individual and if so, how and why?
- 13.4.6. The Inquiry has received evidence from a range of witnesses who have described not being told that they were being tested for HIV and/or HCV and/or HBV. Could finding out subsequently that such testing was carried out without their consent impact on the psychological experience of the individual and if so, how and why?
- 13.4.7. The Inquiry has received evidence from a range of witnesses who have described not being told of their infections for years after their infected status was known by clinicians. Could this withholding of information about their diagnosis impact on the psychological experience of the individual and if so, how and why?
- 13.4.8. The Inquiry has received information from a range of witnesses who have described being given little or no information about their infection, prognosis and/or treatment. Could this impact on the psychological experience of the individual and if so, how and why?
- 13.4.9. Please consider and discuss whether the circumstances in which a person is infected, and/or the circumstances in which a person or their family and loved ones learn about that infection, may impact on the grieving process in the event of the death of the person infected.

- 13.5. Psychosocial impact of financial hardship and dependence: Please consider and discuss the psychosocial impact of financial hardship and/or of dependence upon financial assistance from the trusts and schemes established by central government. You will note from the material that is being provided to you that the Inquiry has received evidence from a range of witnesses about their experiences in dealing with the trusts and schemes.
- 13.6. Please consider and discuss the psychosocial impact for people infected and affected by waiting for many years for explanations, apologies, investigations and/or answers as to what happened and why.
- 13.7. Stigma and discrimination: The Inquiry has received evidence from a range of witnesses who have described the stigma and discrimination of being diagnosed or having a person close to them diagnosed with HIV and/or HCV and/or HBV, particularly in the 1980s and 1990s. How does stigma and discrimination affect a person's psychological and social experiences? Please consider from the perspective of both a person infected and affected.
- 13.8. Access to treatment: The Inquiry has received evidence from a range of witnesses who have described difficulties in accessing treatment for the conditions with which they have been infected. Could this impact on the psychological experience of the individual and if so, how and why?
- 13.9. Care and support: What sort of psychosocial care and support should be available for a person diagnosed with a life threatening disease on first being diagnosed and as the disease progresses?
- 13.9.1. What sort of psychosocial care and support should be available for a person who has been informed that they might be at risk of having been exposed to vCJD (there being no diagnostic test to determine if a living person is so infected)?



- 13.9.2. What sort of psychosocial care and support should be available for an affected individual (e.g. partners, children, parents, families, carers and others close to those infected) both during an infected person's illness and after bereavement?

### **Further evidence**

14. If there are issues on which you consider that you require further evidence before being able to reach a conclusion on some of the topics above, then please set that out in the report or in a separate letter to me. Where practicable, the Inquiry will seek to obtain such evidence as you require and provide it to you. The written statements of the witnesses who have given oral evidence so far, and the transcripts of their oral evidence, are publicly available on the Inquiry's website.
15. Where appropriate, you should provide provisional answers to the questions set out above, qualifying them as necessary with reference to further evidence or research that may be required to provide a more complete answer.
16. 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.
17. 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.
18. 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.

19. 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.
20. The Inquiry will be instructing 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**

21. 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.
22. 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**

23. In preparing your report please make sure that:
  - 23.1. It sets out details of the qualifications of all members of the group and their academic and/or professional experience.
  - 23.2. It gives details of any literature or other material which you have relied on.

- 23.3. It contains a statement setting out the substance of all facts and instructions which are material to the opinions expressed.
- 23.4. It makes clear which of the facts stated are within your knowledge.
- 23.5. 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.
- 23.6. 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.
- 23.7. It contains a summary of your conclusions.
- 23.8. It sets out any qualification to an opinion or conclusion provided.
- 23.9. It contains a statement that each of the group members understands their duty to provide independent evidence and has complied with that duty.
24. 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:*
- (i) I have made clear which facts and matters referred to in this report are within my knowledge and which are not.*
  - (ii) Those that are within my knowledge I confirm to be true.*
  - (iii) The opinions I have expressed represent my true and complete professional opinions on the matters to which they refer.”*
25. 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.

26. 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.
27. I would be grateful if in general you, Professor Weinman, would undertake to be the point of contact for all correspondence between the group and the Inquiry.

### **Timetable**

28. I would be grateful if you can provide a draft copy of your report by 31 December 2019. The Inquiry's oral hearings are underway and the Inquiry wishes to hear evidence arising from your report in oral hearings in late February 2020.
29. 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.
30. 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.
31. One or more members of the group will be asked to attend the Inquiry to give oral evidence in late February 2020.
32. 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**

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

## **Next Steps**

34. 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.

35. 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.

36. 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,



Moore Flannery

Infected Blood Inquiry, Secretariat.