



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

23.12.2019

Professor John 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 supplemental instructions in relation to the report which is being prepared by the group. This letter should be read together with the initial letter of instruction dated 25 September 2019 and the basis upon which you are instructed remains as set out in that letter.
2. The Inquiry has received suggestions from Core Participants to the Inquiry for additional matters to be included in your report and for some of the questions in the initial letter of instruction to be expanded. The purpose of this supplemental

letter is to ask you to address the matters set out below, which have been raised by Core Participants and are appropriate to address at this stage of the Inquiry, along with those questions set out in the initial letter of instruction. The additional questions have been divided into two parts. The first part comprises the questions posed in paragraphs 5 to 13 below - you have indicated that the group will be able to address these in the report which is already being prepared in accordance with the initial letter of instruction. The second part comprises the questions posed in paragraphs 14 to 24 below - you have indicated that these matters will require further work to be undertaken and may have to be addressed in a supplemental report. Please let me know when you think the group will be able to complete the second part of the work.

3. We remind you that we are not asking you to consider or comment on the experiences of any particular individual.
4. As before, the topics and questions set out below are for the most part framed in broad terms, with the aim of allowing the group to approach the matters as you see fit.

Supplemental instructions: part one

5. When answering the questions posed in paragraph 13 of the initial letter of instruction, please ensure that you consider whether the impact is any different for those who have been infected with more than one infectious disease, and if so, why.
6. When answering question 13.1 and 13.3 please address the psychological and social impacts of:
 - 6.1. Living with the possibility that a person might develop other associated illnesses or complications arising from their diagnosed infections.

- 6.2. Living with the knowledge that their condition could deteriorate in the future.
 - 6.3. Living with uncertainty and fear about whether other (as yet unknown) latent illnesses or infections may yet be identified.
 - 6.4. For those people who have cleared a virus, living with the fear that the virus may return.
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7. Please consider, as part of your answers to question 13.1, 13.2 or 13.7, the psychological impact on those infected of the (erroneous) assumptions frequently made by medical staff, schools, employers and wider society as to the aetiology/cause of the infectious diseases contracted.
 8. When answering question 13.4.6 please be aware that the Inquiry has heard evidence from witnesses who have described samples being taken from them for testing without their consent and later being used in medical studies or research. Could finding out subsequently that such testing was carried out without consent and that the results were used in medical studies or research impact on the psychological experience of the individual and if so, how and why?
 9. When answering question 13.4.8 please ensure that you consider the impact of not being informed, or not being given adequate information, about the possible side effects of treatment and/or the after-effects of treatment.
 10. When answering question 13.7 and/or 13.8 please be aware that the Inquiry has heard evidence from a number of witnesses who have described being treated differently as a result of their infection, or the infection of a relative, including: people being segregated during hospital stays (including for child birth), people routinely being put to the end of the day's treatment list and people being treated by clinicians in full protective clothing (for example, more than one witness has described being treated by staff dressed in 'space suits'). How might such experiences further impact upon trust in the medical profession and NHS (question 13.2)?

11. When answering question 13.7 (which asks about the impact of stigma and discrimination), please explore and discuss the psychological and social impact of those infected and affected of not telling their family (including their closest relatives, such as parents or siblings or children), friends, employers and colleagues about their infections; of having to keep their infection and its consequences secret; of (in the words of more than one witness) having to “live a lie”. Please consider also when answering this question what the impact might be of a clinician advising their patient to keep the infection a secret.

12. Question 13.2 of the initial letter of instruction asks you to consider the impact of loss of trust in treating clinicians, the medical profession and the NHS. Please also explore and discuss the psychological and social impact on those infected and affected of a loss of trust, or lack of trust, in the state more generally, and in particular the psychological and social impact on a person who has experienced incidents which could suggest a cover up or lack of candour on the part of the state or an NHS body or other organisation (such as missing medical records or a failure to provide information as to what has happened).

Supplemental instructions: part two

13. When answering question 13.1 please also consider the psychological impact on a parent or carer who:
 - 13.1. actually administered the treatment (such as factor VIII) to a child or other family member who was infected in consequence of that treatment; and/or
 - 13.2. took decisions (such as agreeing to home treatment with factor VIII) about their child’s treatment, where the child was then infected in consequence of that treatment.

How could this impact on their relationship?

14. When answering question 13.1 please explore and discuss the psychological impact on those infected of:

14.1. Living with the fear and uncertainty as to whether they have infected or may infect partners/family members and children (including unborn children).

14.2. Living with the knowledge that they have (unwittingly) put others at risk of infection, even where no infection has been passed on.

14.3. Living with the realisation that they have infected someone else.

(Please note when considering and answering this question and/or question 13.4.8 that some witnesses have stated that they were not given adequate advice or information about safe sex or how to prevent transmission of infection by other means).

15. When answering question 13.1 please explore and discuss the psychological impact on those affected of living with the fear and uncertainty as to whether they have been, or may be, infected.

16. When answering question 13.1 please address the psychological impacts of facing a shortened lifespan as a result of having been infected.

17. When answering question 13.5 please also consider and discuss the psychosocial impact of also being dependent on state benefits and all that entails in terms of the application and assessment and re-assessment processes required to claim and retain welfare benefits. In particular please consider how the effects of infection and illness might impact on a person's ability to engage with this process.

18. When answering question 13.6 please consider:

18.1. The psychological impact arising from the fact that many of those infected and affected have died (and that deaths continue to occur) while waiting.

18.2. The psychological and social impact of actively campaigning for answers and an investigation, over many years (and for some, for their whole lives).

19. Question 13.3 of the initial letter of instruction asked you to consider, as part of your discussion of the social impacts of infection, matters such as deciding not to have or being unable to have children. Please also consider the psychological impacts of such matters, including making a decision not to have children in consequence of infection; making a decision to terminate a pregnancy in consequence of infection; being unable to have children in consequence of the infection or the side-effects of treatment; having to undergo additional procedures (e.g. sperm washing) in an attempt to have children.
20. Please explore and discuss the psychological impact of undergoing treatment to clear an infectious disease and of the treatment then failing. Does the impact change if there is more than one failed round of treatment? If so, why? Does the impact change if the person experienced negative symptoms during the failed treatment?
21. Please consider the psychological impact on a person who has been told that they have, or may have, been exposed to a potentially fatal disease (such as vCJD) and is then told shortly afterwards that they most probably have not.
22. Please explore and discuss the psychological impacts of a patient being given experimental treatments by way of clinical trials. Is this impact different to a patient receiving ordinary treatment, and if so how and why?
23. Please explore the psychological impact of a person discovering that they were or may have been identified as a previously untreated patient and were then given treatment and became infected.
24. Please explore the psychological impacts on wider family members and through further generations.

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

26. May I thank you and the other group members once again for agreeing to assist the Inquiry. I am pleased that Myfanwy Morgan has accepted the nomination to join the group. 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.