SUPPLEMENTAL LETTER OF INSTRUCTION

TO THE CLINCIAL GROUP: HIV

20.12.2019

Professor Jane Anderson

Dear Professor Anderson

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 20 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. I understand that it is likely that you will not be able to provide that report until 6 January 2020. The second part comprises the questions posed in paragraphs 21 to 23 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 question 14.1 in the initial letter of instruction please include a description of any other terms that have been used to describe the virus now known as HIV and when those terms ceased to be used.

6. Please note when answering question 14.2 that whilst the focus of the question is the emergence of HIV in the UK it will be of assistance to the Inquiry if your report also considers the wider international background.

7. When answering question 14.4 please explain:
   7.1. the extent of viral exposure a person requires to become infected;
   7.2. why not everyone exposed to an infected batch of product will become infected;
   7.3. whether repeated exposure to HIV infected products increases the risk of a person becoming infected with HIV;
   7.4. whether repeated exposure to HIV infected products in a person with HIV increases their viral load, and if so, what effect this will have on them.

8. When answering question 14.9 please include an explanation of the monitoring of the viral load and CD4 count, and what the significance of this is for a person with a diagnosis of HIV.

9. When answering question 14.14 please include consideration of whether the standard of the medical treatment a person receives will impact on their prognosis and life expectancy and if so how.

10. When answering question 14.16 please:

10.1. include an explanation as to the extent to which the treatment for HIV affects those with a bleeding or blood disorder differently to people without a bleeding or blood disorder;

10.2. include an explanation as to whether the impact of HIV and the treatment available for HIV is different for a person with a bleeding disorder with an inhibitor;

10.3. provide details of any research or studies you are aware of into the impact of HIV on those with a blood or bleeding disorder in the UK.

11. When answering question 14.17 please address the following questions:

11.1. Would you expect a person to be given any advice or information (and if so, what) about starting a family?

11.2. Would you expect a person to be given an advice or information (and if so, what) about donating blood?

11.2.1. What support would you expect a newly diagnosed person to receive?

11.2.2. What advice, information and support would you expect to be given to the family of a newly diagnosed person?

12. Please add to Annexes 1, 2 and 3, under mental health symptoms, “suicidal ideation and on some occasions suicide attempts”.

13. Are there any guidelines or protocols or any guidance in place currently for those treating people diagnosed with HIV as to when to recommend testing family members or previous sexual partners? What is good clinical practice in this regard?

14. What is the current optimum model of care for a person diagnosed with HIV and/or AIDS? Please ensure that you include:

14.1. palliative care;

14.2. how the care of co-infected people should be managed and coordinated.

15. To the extent that HIV and/or treatment for HIV causes or is linked to other health conditions (such as bleeding disorders) and secondary complications, to what extent should care for HIV and those conditions be co-ordinated, and what is current best practice and the optimum clinical model in this regard?

16. What happens when a person with HIV stops taking their medication?

17. Is it possible for a person with HIV to spontaneously clear the infection and/or can HIV ever be completely cured? What is the likelihood of either of these occurring?

18. Following successful treatment for HIV such that a person has an undetectable viral load, what follow up scans, blood tests and/or checks and treatment should the person receive, how often and over what period of time?

19. What are the current clinical guidelines for infection control when treating a person with HIV?

20. What if any reporting and or data collection methods are used to record secondary health conditions or complications which may have arisen from HIV/AIDS and/or any treatment received for the same?

Supplemental instructions: part two

21. When answering question 14.7 please include consideration of whether Hepatitis G plays a role in slowing down the progress of HIV and whether it affects the latency period or the progress of HIV generally. Are there any other viral agents that may have a similar effect?

22. To what extent, and how, does HIV affect babies and children differently from adults?

23. What training is currently given to medical students and medical professionals who work outside the field of infectious diseases, about HIV and AIDS?

24. 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.

25. For ease of reference, I include in this letter the clarification I sent on 22 November:

> We have been asked by some core participants to clarify one aspect of your letter of instruction. In para. 14.2 of the letter, you have been asked to provide "A history of the emergence of HIV in the UK and what has been understood about HIV and AIDS over the years from its emergence to the present day". We wish to clarify that you are not being asked to give your views on what was or what ought to have been known by clinicians in the 1970s, 1980s or 1990s about HIV, AIDS or the risks of infection. You are being asked to provide, from a modern perspective, a history of the emergence of HIV and the major scientific milestones in understanding and treating the condition; you are not being asked to give an opinion on what a clinician at the time either knew or ought to have known about it.

26. May I thank you and the other group members once again for agreeing to assist the Inquiry. I am pleased that Ian Williams 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,

Moore Flannery
Infected Blood Inquiry, Secretariat.