Witness Name: Dr Bernard McVerry
Statement No.: WITN3502004
Exhibits: None
Dated: 19 November 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DR BERNARD MCVERRY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23 April 2020

I, Dr Bernard McVerry, will say as follows: -

Section 1: Introduction

1. Please set out your name, address, date of birth and professional qualifications.

1.1 My name is Dr Bernard McVerry. My address and date of birth are known to the Inquiry. **My qualifications are MB.Bch Bao MRCP MRCPATH**

2. Please set out your employment history including the various roles and responsibilities that you have held throughout your career, as well as the dates.

2.1 I qualified at University College Dublin in 1969. I then had a one year internship in Dublin and then moved to the US for six years. I spent two years specialising in haematology in Boston. I undertook a research post in coagulation. I had no involvement in the area of Haemophilia either before or whilst in the US. I came to London in 1975 to undertake a temporary post at the Royal Free Hospital in Dr Dormandy's Haemophilia unit. This was largely an outpatient service providing patients with cryoprecipitate. I was there for two to three months.

2.2 I then undertook a position as a Senior Registrar at University College Hospital and was there for approximately five years. I was not involved with haemophiliacs.

2.3 Then in 1980, a senior lectureship became available at the Royal Liverpool Hospital ("RLH") which I accepted.

2.4 In 1985 I moved to St James's Hospital which is part the combined Leeds Teaching Hospitals ("Leeds") as Consultant Haematologist and worked until 68 years of age.

2.5 I retired almost ten years ago. The only experience I had of treating haemophiliacs prior to starting at the RLH was the few months that I spent at the Royal Free in Dr Dormandy's Haemophilia Unit 1975.

3. Please set out your membership, past or present, of any committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

3.1 By the time I left RLH I was acting head of department. During my time in Liverpool I established a regional bone marrow transplant service for Merseyside, the first outside London. This was in addition to my routine clinical activities which included the care of patients with hemophilia and my teaching responsibilities. I was also the University member of the BMA.

3.2 I was a member of the United Kingdom Haemophilia Centre Doctors' Organisation ("UKHCDO") for 1-2 years while in Leeds. I cannot now recall the specific dates. I was just a sitting member. I was not a member of any sub-committee.

4. Please confirm whether you have provided evidence to, or have been involved in, any other inquiries, investigations, criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. Please provide details of your involvement and copies of any statements or reports which you provided.

4.1 I cannot recall if I have provided evidence in connection with any inquiries or investigations or litigation involving HIV, HBV or vCJD. I do not hold or have access to any statements or reports concerning these matters.

Section 2: Decisions and actions of the Royal Liverpool Hospital and the Leeds Haemophilia Centre and your decisions and actions when a clinician there

5. Please describe:

a. the facilities and organisation of the Royal Liverpool Hospital and the Leeds Haemophilia Centre in relation to the treatment of people with bleeding disorders; and

5.1 I have little recollection of the organization of the department and the treatment of patients at RLH. This was between 35 and 40 years ago. I therefore apologies if my answers appear brief or limited. At this time funding was very limited. The unit was largely situated within the Haematology laboratory. I had no dedicated supporting staff. I cannot now remember with any degree of accuracy but I think the patients would be seen usually by a technician and collect their factor 8 from the laboratory.

b. the roles, functions and responsibilities of the Royal Liverpool Hospital and the Leeds Haemophilia Centre during the time that you worked there and how they changed over time.

5.2 The relevant time at RLH was between 25-35 years ago and having retired ten years ago and now being 77 years old I cannot recall what happened at RLH at this time with any degree of detail or accuracy. As far as I can recall there was more funding available at Leeds. While in Leeds central government purchasing of factor 8 occurred, and this released money to the various units, increasing staff report within the unit.

5.3 Leeds had been designated a Haemophilia Centre before I arrived. There was a nurse, whose main role was injecting and supplying factor 8 when required.

6. Please identify senior colleagues at the Royal Liverpool Hospital and the Leeds Haemophilia Centre involved in the care of patients with bleeding disorders and/or patients infected with HIV/hepatitis in consequence of infected blood or blood products, and their roles and responsibilities during the time that you worked there.

6.1 At RLH I had no senior colleague involved in the care of haemophilia patients although I did work with consultant colleagues but they had their own interests which was not haemophilia.

6.2 At Leeds I worked closely with colleagues in the Liver and Infectious Disease Unit and sought their help when required.

7. Please describe:

a. your role and responsibilities at the Royal Liverpool Hospital and the Leeds Haemophilia Centre and how, if applicable, this changed over time;

7.1 At RLH I was a Consultant Haematologist, acting Head of Department, director of the Bone Marrow Transplant Unit and Director of the Haemophilia Service.

7.2 At Leeds I was a Consultant Haematologist where I undertook clinics, ward rounds and teaching. I was also the director of Haemophilia Centre.

b. your work at the Royal Liverpool Hospital and the Leeds Haemophilia Centre insofar as it involved the care of patients with bleeding disorders and/or patients infected with hepatitis and/or HIV in consequence of infected blood or blood products.

7.3 My work at RLH and Leeds involved providing advice and / or therapy to such patients.

8. Approximately how many patients with bleeding disorders were under the care of the Royal Liverpool Hospital and the Leeds Haemophilia Centre when you began your clinics there and over the years that followed? (If you are able to give exact rather than approximate figures, please do so). What proportion were adults and what proportion were children?

8.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy. I would suggest that the Inquiry contacts the respective institutions. I did not treat children at any time in my career.

9. To the best of your knowledge, what decisions and actions were taken, and what policies were formulated, by the Royal Liverpool Hospital and the Leeds Haemophilia Centre, regarding the importation, manufacture and use of blood products (in particular factor concentrates) during the time that you worked there? What, if any, involvement did you have in these decisions?

9.1 I was at RLH between 35-40 years ago, so I cannot recall there with any degree of detail or accuracy. I would have chosen the products to prescribe. I believe that the eventual choice of product in Liverpool would have been made following a discussion with Peter Jones, a highly regarded Haemophilia expert in Newcastle. As far as I can recall he had transferred his patients to commercial factor 8 to address the lack of NHS available factor concentration.

9.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy. But, by the time I came to Leeds as recombinant products or heat treated products were available these would have been used.

10. What responsibility did the Royal Liverpool Hospital and the Leeds Haemophilia Centre have for the selection and purchase of blood products, and what decisions were taken by the Royal Liverpool Hospital and the Leeds Haemophilia Centre as to which products to purchase and use? In addressing this issue, please answer the following questions:

10.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age again I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

a. How, and on what basis, were decisions made about the selection and purchase of blood products?

10.2 As far as I can recall the choice of product would have been mine as the consultant, based upon what was available at the time to the respective institutions.

b. What were the reasons or considerations that led to the choice of one product over another?

10.3 I cannot now recall specific details but generally the product choice would have been influenced by the lack of UK manufactured Factor 8 concentrates being readily available and a discussion with Peter Jones of Newcastle which I mention above.

c. What role did commercial and/or financial considerations play?

10.4 With the caveat on my recollections that have been previously expressed I would say none.

d. What, if any, involvement did you have?

10.5 Please see my answer to question 9 above.

11. What particular products were used for treating patients at the Royal Liverpool Hospital and the Leeds Haemophilia Centre, over what period of time and for which categories of patients?

11.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at this time in Leeds with any degree of detail or accuracy.

11.2 However, as far as I can recall, generally at RLH this would have been a mixture of NHS and commercial Factor 8 and then heat treated Factor 8.

11.3 At Leeds, heat treated and then recombinant products.

12. What was the relationship between the Royal Liverpool Hospital and the Leeds Haemophilia Centre and the pharmaceutical companies manufacturing/supplying blood products? What influence did that relationship have on the decisions and actions of the Royal Liverpool Hospital and the Leeds Haemophilia Centre?

12.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. Also the relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

12.2 However, as far as recall there was no relationship. We would have seen company representatives to discuss their products. No money was paid, but there would have been some sponsorship of educational meetings, which would have been in common with other similar institutions. There would have been no influence on me by these companies to purchase a particular product.

13. If the responsibility for the selection and purchase of blood products lay with an organisation other than the Royal Liverpool Hospital and the Leeds Haemophilia Centre, please specify which organisation and provide as much information as you can about its decision-making.

13.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. Also, the relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

13.2 As a consequence I cannot now recall specifically how these decisions were made. I think initially these would have been taken at a local level. Later there was a move to central purchasing. There was a tendency to keep individual patients on the same product due to a concern that Factor 8 antibodies might appear. I also think, but cannot be sure, that UKHCDO thought that a number of commercial companies should be used for commercial factors rather relying on only one preferred supplier.

14. How were decisions taken as to which products to use for individual patients? What involvement did you have in such decisions?

14.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. Also, the relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77

years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

14.2 However, as consultant, this would have been my decision in conjunction with senior haemophilia nurses, based on the products that were available to me at the respective institutions.

15. What alternative treatments to factor concentrates were available for people with bleeding disorders?

15.1 The general alternatives would have included cryoprecipitate, DDAVP and FFP plasma.

16. What were, in your view, the advantages and disadvantages of those alternative treatments? What use did the Royal Liverpool Hospital and the Leeds Haemophilia Centre make of them? Do you consider that they should have been used in preference to factor concentrates so as to reduce the risk of infection? If not, why?

16.1 As far as I can now recall they could have been used in mildly affected patients who needed to be given medication in hospital. I do not think that they would have been use for HIV, Hepatitis C patients.

17. What was the policy and approach of the Royal Liverpool Hospital and the Leeds Haemophilia Centre as regards the use of cryoprecipitate for the treatment of patients with bleeding disorders?

17.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy.

17.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy and so I cannot say what the policy and approach was for the use of cryoprecipitate.

a. Did that policy and approach change over time and, if so, how?

17.3 Please see my answer to question 17 above.

b. How, if at all, was the policy and approach informed by discussions with external parties?

17.4 Please see my answer to question 17 above.

18. What was the policy and approach of the Royal Liverpool Hospital and the Leeds Haemophilia Centre in relation to home treatment? Did the policy and approach change over time and, if so, how?

18.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. Also, the relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

18.2 However in general it was thought that home therapy would be much easier for suitable patients, and after its introduction the patients preferred this.

19. What was the policy and approach of the Royal Liverpool Hospital and the Leeds Haemophilia Centre in relation to prophylactic treatment? Did the policy and approach change over time and, if so, how?

19.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy.

19.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

19.3 However in general terms it was encouraged for suitable patients.

20. What was the policy and approach of the Royal Liverpool Hospital and the Leeds Haemophilia Centre in relation to the use of factor concentrates for children? Did the policy and approach change over time and, if so, how?

20.1 I did not treat, or advise in relation to, children.

21. To what extent, and why, were people with mild or moderate bleeding disorders treated with factor concentrates?

21.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy.

21.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

21.3 However, in general terms, as far as I can recall, the possible reasons for treating this cohort with factor concentrates could include: post-surgery DDAVP tachyphylaxis; life threatening bleeding; and poor response to DDAVP.

22. What viruses or infections, other than HIV, HCV and HBV, were transmitted to patients at the Royal Liverpool Hospital and the Leeds Haemophilia Centre in consequence of the use of blood products?

22.1 With the caveat of not being able to recall specifics of between 25 and 40 years ago, I cannot recall any other viruses or infections.

Section 3: Knowledge of, and response to, risk

General

23. When you began work as a Haematologist at the Royal Liverpool Hospital what did you know and understand about the risks of infection associated with blood and/or blood products? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

23.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened during this period with any degree of detail or accuracy.

23.2 The only experience I had of treating haemophiliacs prior to starting at the RLH was the few months that I spent at the Royal Free in Dr Dormandy's Haemophilia Unit 1975.

Consequently when I started at RLH in 1980, I would have known little, if anything, about the risks of infection associated with blood and / or blood products.

23.3 What I subsequently learned would have been from haematology journals, haematology meetings and the like. With time and becoming more familiar with certain colleagues and being aware of the developing situation my knowledge would have improved.

24. What advisory and decision-making structures were in place, or were put in place at the Royal Liverpool Hospital and the Leeds Haemophilia Centre and/or within the area covered by these two hospitals and/or nationally, to consider and assess the risks of infection associated with the use of blood and/or blood products?

24.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy. I would therefore suggest contacting the respective institutions.

25. What was your understanding of the relative risks of infection from (i) the use of commercially supplied blood products, and (ii) the use of NHS blood products?

25.1 I assume that the time period for this is as referred to in question 23 and if this is so I am unable to answer this question.

26. What decisions and actions were taken by the Royal Liverpool Hospital and/or the Leeds Haemophilia Centre and/or by you to minimise or reduce exposure to infection?

26.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy.

26.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot recall what happened at Leeds at this time with any degree of detail or accuracy.

26.3 I am unable to answer this question and so I would suggest contacting the respective institutions.

Hepatitis

27. When you began work as a Haematologist at the Royal Liverpool Hospital, what was your knowledge and understanding of the risks of the transmission of hepatitis (including hepatitis B and NANB hepatitis/hepatitis C) from blood and blood products? What were the sources of your knowledge? How did that knowledge and understanding develop over time?

27.1 This is now 35 to 40 years ago and so I have no detailed or accurate memory in relation to this. However, as far as I can recall when I began work at RLH in 1980 there was some knowledge of the risk of transmission of Hepatitis B but I believe that in 1980 there was no recognised Hepatitis C/NANB hepatitis, this was only reflected by idiopathic abnormal liver function tests.

28. What, if any, further enquiries and/or investigations did you carry out or cause to be carried out in respect of the risks of the transmission of hepatitis? What information was obtained as a result?

28.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. However, I anticipate that I would have liaised with the hepatology team for my patients.

29. What, if any, actions did you take to reduce the risk to patients of being infected with hepatitis (of any kind)?

29.1 I was at RLH between 35 and 40 years ago and so I cannot recall what happened at RLH with any degree of detail or accuracy. However, as far as I can recall, patients would be assessed in clinics and the products and the prescriptions that they were receiving would be reviewed.

30. What was your understanding of the nature and severity of the different forms of blood borne viral hepatitis and how did that understanding develop over time? When answering this question please comment on the minutes of the 11th

UKHCDO meeting [BART0002485] held on 30 September 1980 (attended by you) in which it was noted that:

a. There were problems obtaining post-mortem reports on haemophiliac patients because pathologists did not want to undertake post-mortems due to the risk of being infected with hepatitis; and

b. NHS product and small pool concentrates would decrease the incidence of hepatitis in the haemophiliac population.

30.1 The 11th UKHCDO meeting was on the 30 September 1980, 40 years ago. I cannot recall what was discussed at this meeting and therefore cannot say whether the minutes of this meeting that have been provided are an accurate representation of what was discussed at that meeting. I believe that in 1980 there was no recognised Hepatitis C, NANB hepatitis, this was only reflected by idiopathic abnormal liver function tests. I have no recollection regarding a reluctance to provide post-mortems in 1980, although I am not saying that this was not the case. Cryoprecipitate therapy could not be safely undertaken at home and therefore would have required patients to have been treated in hospital which patients were reluctant to do.

HIV and AIDS

31. What was your knowledge and understanding of HIV (HTLV-III) and AIDS and, in particular, of the risks of transmission from blood and blood products during your time working at the Royal Liverpool Hospital and/or the Leeds Haemophilia Centre? How did your knowledge and understanding develop over time?

31.1 With my limitation of recollections now of what happened between 25 and 40 years ago, generally, knowledge of HIV was poor before the end of 1983. Reliable tests for HIV only became available during 1985 and for Hepatitis C 1991 - 1992, both of which improved the situation for testing patients with these conditions.

32. How and when did you first become aware that there might be an association between AIDS and the use of blood products?

32.1 Again I cannot say with any degree of accuracy but this may have been at the end of 1983 / beginning of 1984.

33. What, if any, enquiries and/or investigations did you and/or the Royal Liverpool Hospital and / or the Leeds Haemophilia Centre carry out or cause to be carried out in respect of the risks of transmission of HIV or AIDS? What information was obtained as a result?

33.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy.

33.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy.

33.3 Please contact the relevant institution.

34. What, if any, actions did you and/or the Royal Liverpool Hospital and / or the Leeds Haemophilia Centre take to reduce the risk to your patients of being infected with HIV?

34.1 Please see my answer to question 33 above. I think that there was a switch to alternative products but please contact the relevant institution.

35. Did the Royal Liverpool Hospital and/or the Leeds Haemophilia Centre continue to use factor concentrates to treat patients, after becoming aware of the possible risks of infection of HIV? Why?

35.1 Please see my answer to question 33 above.

Response to risk

36. Did you or your colleagues at the Royal Liverpool Hospital and the Leeds Haemophilia Centre take steps to ensure that patients were informed and educated about the risks of hepatitis and HIV? If so, what steps?

36.1 With my limitation of recollections now of what happened between 25 and 40 years ago I am not able to say what steps were taken to inform and educate about the risk of hepatitis and HIV.

37. When did the Royal Liverpool Hospital and/or the Leeds Haemophilia Centre begin to use heat treated factor products and for which categories of patients? You wrote to Dr Snape on 19 February 1985 [CBLA0002051] asking for heat treated Factor VIII concentrate for named patients. What led you to take this step? How did you choose which patients went on that list? Did you make any attempt to obtain heat treated factor products earlier than February 1985?

37.1 I do not recall writing the letter to Dr Snape of 19 February 1985 from over 35 years ago. My letter is self-evident and I cannot add anything further.

38. Did you experience difficulties and/or delays in obtaining heat treated products?

38.1 Please see my response to question 37, I do not remember, my recollections of my time at RLH are poor.

39. Do you consider that heat-treated products should have been made available earlier? If not, why?

39.1 Please see my answers to 37 and 38 above

40. Did you or your colleagues at the Royal Liverpool Hospital and/or the Leeds Haemophilia Centre revert to treatment with cryoprecipitate for some or all of the patients in response to the risk of infection? In answering this question please comment on [ARCH0002566] the minutes of the 14th meeting of UKHCDO which you attended on 17 October 1983 at which Dr Chisholm suggested that in view of the AIDS 'scare' it might be appropriate to revert to cryoprecipitate for home treatment particularly as there were problems sourcing commercial concentrates, but there were unlimited supplies of cryoprecipitate available. Did you agree with the conclusion of the meeting that patients should not be encouraged to go over to cryoprecipitate for home therapy? If so, why? If not, why not? How did you respond to this issue?

40.1 The 14th UKHCDO meeting was 37 years ago. I cannot recall what was discussed at this meeting in any detail. However, I believe that Dr Bloom was not in favour of a return to the use of cryoprecipitate, the motion to revert to cryoprecipitate therapy was

not carried and so doctors were not encouraged to change from the use of factor concentrates.

41. If you or your colleagues did revert to treatment with cryoprecipitate, when did this occur, how was it determined which patients would be offered a return to cryoprecipitate and which would not? If you or your colleagues did not revert to treatment with cryoprecipitate, why not?

41.1 I do not now recall if there was a reversion to using cryoprecipitate.

42. Do you consider that your decisions and actions, and those of the Royal Liverpool Hospital and the Leeds Haemophilia Centre in response to any known or suspected risks of infection were adequate and appropriate? If so, why? If not, please explain what you accept could or should have been done differently.

42.1 I do not recall any decisions or actions referred to in this question. However, with the benefit of hindsight, better oversight of the products prescribed to patients should have been employed in particular the use of commercial Factor 8.

43. Looking back now, what decisions or actions by you and/or by the Royal Liverpool Hospital and/or the Leeds Haemophilia Centre could and/or should have avoided, or brought to an end earlier, the use of infected blood products?

43.1 Please see my answer to question 42.

44. What actions or decisions or policies of other clinicians or other organisations, within your knowledge, played a part in, or contributed to, the scale of infection in patients with bleeding disorders? What, if anything, do you consider could or should have been done differently by these others?

44.1 Please see my answer to 42.

45. Do you consider that greater efforts could and/or should have been made to inactivate viruses in blood or blood products prior to 1980? If so, who should have made or coordinated those efforts and what steps should have been taken and when? If not, why?

45.1 Please see my answer to question 2. Apart from 2 - 3 months in 1975 I was not treating haemophilia patients prior to 1980.

Section 4: Treatment of patients at the Royal Liverpool Hospital and the Leeds Haemophilia Centre

Provision of information to patients

46. What information did you provide or cause to be provided (or was, to your knowledge, provided by others) to patients at the Royal Liverpool Hospital and the Leeds Haemophilia Centre with a bleeding disorder about the risks of infection in consequence of treatment with blood products (in particular, factor concentrates) prior to such treatment commencing? Please detail whether, and if so, how this changed over time.

46.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy.

46.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy.

46.3 Consequently I cannot now recall what patients were told. I suspect that at the beginning of the period the information provided to patients was not as thorough as it was subsequently as our understanding developed and improved with time.

47. What information did you provide or cause to be provided (or was, to your knowledge, provided by others) to patients about alternatives to treatment with factor concentrates? Please detail whether, and if so, how this changed over time.

47.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy and in particular what information was provided to patients about alternatives to treatment with factor concentrates or the detail of any instruction given to patients when they began home therapy.

47.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy and in particular what information was provided to patients about alternatives to treatment with factor concentrates.

48. What information did you provide or cause to be provided (or was, to your knowledge, provided by others) to patients before they began home treatment/home therapy?

48.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy and in particular the detail of any instruction given to patients when they began home therapy.

48.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy and in particular the detail of any instruction given to patients when they began home therapy.

HIV

49. When did you first discuss AIDS or HIV (HTLV-III) with any of your patients?

49.1 I cannot now recall.

50. Please describe how and when you learned that patients under your care had been infected with HIV.

50.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy.

50.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy.

50.3 However, I refer to my answer above to question 31. I thought that it was unsafe to commit to a diagnosis of HIV without reliable tests being available..

51. What tests were undertaken for HIV, where, by whom and over what period of time?

51.1 Please see my answer to 50 above. However, as far as I can now recall when I transferred to Leeds in mid 1985 tests would have been undertaken at clinic visits either requested by me or Dr Swinburn, as initially we undertook joint clinics.

52. What if any arrangements were made for pre-test counselling?

52.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy.

52.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy.

52.3 In any event I am not sure what is meant by counselling. As far as I can recall there would have been discussions in the clinic.

53. How and when, and by whom, were patients told that they had been, or might have been, infected with HIV? Were they told in person, by letter or by phone? Were they seen individually or in groups? What, if any, involvement did you have in this process?

53.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy. However, I refer to my answer to question 31 and 50 above. I thought that it was unsafe to commit to a diagnosis of HIV without reliable tests being available

53.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy. However, I anticipate that I would have had the discussion with the patient.

54. Were you aware of any discussions among clinicians about whether they should or should not tell their patients (and, in relation to children, their families) of their HIV infection? If you were aware of such discussions, when and where did they happen, and what reasons were considered and discussed for informing or not informing people that they had HIV?

54.1 Generally I worked alone so I cannot recall any such discussion.

55. What information was given to patients about the significance of a positive diagnosis? Were patients told to keep their infection a secret? What information was provided about the infection, prognosis, treatment options and management? What were they told about the source of the infection?

55.1 I cannot now recall anything specific, however in general terms if a reliable positive diagnosis had been obtained, patients would not have been told to keep the diagnosis a secret, but disclosure would have been for the patient to decide (although family should be aware).

56. What was the policy and approach in relation to testing partners/family members of people known or suspected to be infected with HIV? Under what circumstances were these tests carried out?

56.1 I cannot now recall the precise policy and approach in relation to testing partners / family members of people known or suspected to be infected with HIV. However, the general approach would be that if the patient had a reliable positive test result, the patient would be advised that the patient's partner could come in for a test, but there would have been a reliance on the patient passing on this invitation to the partner. Some patients did not want partners to know of their infected status.

57. What, if any, information or advice was provided by you or colleagues to partners or family members of people who were at risk of infection with HIV or were infected with HIV?

57.1 I cannot now recall the precise information or advice provided to partners or family members. However, please see my response to 56 above. Generally, if the partner then attended the clinic it would be explained that the patient had had a positive test

result and that the partner would need a blood test to check for infection. I cannot recall what advice would have been given following this.

58. What, if any, arrangements were made for post-test counselling?

58.1 I cannot now recall.

59. How many patients at (a) the Royal Liverpool Hospital and (b) the Leeds Haemophilia Centre were infected with HIV? Of those infected:

a. How many had severe haemophilia A?

b. How many had moderate haemophilia A?

c. How many had mild haemophilia A?

d. How many had haemophilia B or von Willebrand's disease?

e. How many were children?

59.1 I cannot recall any numbers. The respective institutions may be able to assist with this. I did not treat children.

60. Was work undertaken at the Royal Liverpool Hospital and/or the Leeds Haemophilia Centre to establish the time period during which patients seroconverted? If so, please describe what work was done and what if any conclusions were reached.

60.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy.

60.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy.

60.3 However, as far as I recall now, no work was undertaken at the RLH and / or Leeds to establish the time period during which patients seroconverted.

Hepatitis B

61. Were patients infected with hepatitis B informed of their infection and, if so, how?

61.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy. Also the relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy. However, as far as I can recall this probably would have been in clinic but I cannot recall anything specific about what would have been said.

62. What information was provided to patients infected with hepatitis B about the infection, its significance, prognosis, treatment options and management? What if any involvement did you have in this process?

62.1 Please see my answer to question 61.

63. How many patients at the Royal Liverpool Hospital and the Leeds Haemophilia Centre were infected with hepatitis B?

63.1 Please see my answer to question 61.

NANB Hepatitis/Hepatitis C

64. Were patients infected with NANB hepatitis informed of their infection and, if so, how and by whom?

64.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy. Also the relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy. However, as far as I can recall generally, abnormal LFTs were not uncommon in the population. As

there was no diagnosis for some time, all a patient and their family members could be told was that the LFTs were abnormal and that there could be a number of causes of this.

65. What information was provided to patients infected with NANB hepatitis about the infection, its significance, prognosis, treatment options and management? What if any involvement did you have in this process?

65.1 Please see my answer to question 64.

66. When did the Leeds Haemophilia Centre begin testing patients for hepatitis C? You were part of the UKHCDO on 7 October 1991 when in a meeting (which you did not attend but in respect of which you will presumably have received the minutes [PRSE0002012]), a recommendation was made that all haemophiliacs should be tested for hepatitis C, and all those tested by first generation tests should be retested using second generation tests. Did you act on that recommendation? If not, why not?

66.1 The relevant time at Leeds is probably around 28-29 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy. However, as far as I can recall generally I would say that testing probably started in late 1991 or early 1992 and these would have been PCR tests.

67. Were patients informed of their hepatitis C infection? If so, how, when and by whom? Were they told in person, by letter or by phone? What, if any, involvement did you have in this process?

67.1 Please see my answer to question 66. Generally patients would probably have been informed by me in clinic but I have no specific recollection of doing this.

68. What information was provided to patients infected with hepatitis C about their infection, its significance, prognosis, treatment options and management?

68.1 The relevant time at Leeds is probably around 28-29 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy. However, as

far as I can recall generally I would say that information would have been provided about the infection, its significance, prognosis, treatment options and management but I cannot recall the specifics of what they would have been told.

69. How many patients at the Leeds Haemophilia Centre were infected with hepatitis C?

69.1 I cannot recall any numbers, the respective institutions may be able to assist with this.

Delay/public health/other information

70. Were the results of testing for HIV and hepatitis (of all kinds) notified to patients promptly, or were there delays in informing patients of their diagnosis? If there were delays in informing patients, explain why.

70.1 I am unsure what is meant by *"promptly"* or *"delays"*. Please see my answers to questions 31, 50, 53 and 55.

71. To what extent, if at all, did you/your colleagues take into account the public health implications of HIV, AIDS, hepatitis B, NANB hepatitis and hepatitis C, when making decisions as to what information or advice to provide to patients or what treatment to offer patients?

71.1 I cannot answer this question as no indication is given as to what it is suggested the public health implications were or that are being referred to between 25 and 40 years ago.

72. What information was provided to patients about the risks of other infections?

72.1 I do not understand what other infections are being referred to in this question and so I am unable to answer.

73. What information was provided to patients about the risks of infecting others?

73.1 I do not understand what infections are being referred to in this question and so I am unable to answer.

74. What actions or decisions were taken by Royal Liverpool Hospital and the Leeds Haemophilia Centre to trace patients who may have been infected through the use of blood or blood products?

74.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy. Also the relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy. I anticipate that the relevant institutions may be able to provide the Inquiry with the appropriate information

Consent

75. How often were blood samples taken from patients attending the Royal Liverpool Hospital and the Leeds Haemophilia Centre and for what purposes? What information was given to patients about the purposes for which blood samples were taken? Did the patients give informed consent to the storage and use of the samples?

75.1 The question is non-specific. I cannot now recall how frequently blood samples were taken although generally bloods would be taken at review appointments as these were haematology reviews. I cannot recall what specific information was given to patients about the purpose for which blood samples were taken and I cannot now recall whether samples were stored.

76. Were patients under your care or under the care of your colleagues at the Royal Liverpool Hospital and the Leeds Haemophilia Centre treated with factor concentrates or other blood products without their express consent? If so, how and why did this occur? What was your approach to obtaining consent to treatment?

76.1 I cannot recall how frequently blood samples were taken although generally bloods would be taken at review appointments as these were haematology reviews. I have no reason to believe that the approach to consent during this period was different to other institutions and the general evidence on consent given to the Penrose Inquiry.

77. You were present at a meeting of the UKHCDO on 5 June 1995 [HCDO0000454] at which it was agreed that some form of written consent should be obtained from patients before they were given blood products for the first time. Did you agree to and follow this recommendation? Was this a change to your practice? Prior to that how did you seek the consent of patients to treatment and how (if at all) was that recorded?

77.1 I do not recall attending a meeting of the UKHCDO on 5 June 1995 (over 25 years ago). I cannot now recall what was happening at this time with any degree of detail or accuracy. However, I have no reason to believe that the approach to consent at this time was different to other institutions and as described in general evidence on consent given to the Penrose Inquiry.

78. Were patients under your care tested for HIV or hepatitis or for any other purpose without their express consent? If so, how and why did this occur? What was your approach to obtaining consent for testing?

78.1 Due to the passage of time and the quality of my recollections from between 25 and 40 years ago I can only give a general answer. However, I have no reason to believe that the approach to consent during this period was different to other institutions and in general evidence on consent given to the Penrose Inquiry.

PUPS

79. Please detail all decisions and actions taken at the Royal Liverpool Hospital and the Leeds Haemophilia Centre by you or with your involvement with regard to a category of people referred to as 'previously untreated patients' (PUPS).

79.1 Due to the passage of time and the quality of my recollections from between 25 and 40 years ago I can only give a general answer. However, as far as I can now recall, PUPs were very rare. The general approach for PUPs would probably have been that if treatment was required to first treat with DDAVP, if this was not viable, then Cryoprecipitate and F8 only in the case of an emergency.

80. Please note the minutes of the meeting of UKHCDO Executive Committee on 3 February 1997 [BART0000955] in which you are recorded as agreeing with the

comment made by Dr Jones that he would 'refuse to give PUPs plasma derived products.'

a. What did you mean by this?

b. Was it your practice not to give PUPs plasma derived products? If so, why?

c. Did you use the term PUP or PUPS when speaking about or referring to any of your patients? If so, what did you mean by the use of the term?

80.1 Please see my answer to question 79 above.

Research

81. Please list all research studies that you were involved with during your career and in particular during your time as a consultant at the Royal Liverpool Hospital and the Leeds Haemophilia Centre that could be relevant to the Inquiry's Terms of Reference. In relation to each of them, please:

a. Describe the purpose of the research.

b. Explain the steps that were taken to obtain approval for the research.

c. Explain what your involvement was.

d. Identify what other organisations or bodies were involved in the research.

e. State how the research was funded and from whom the funds came.

f. State the number of patients involved.

g. Provide details of steps taken to inform patients of their involvement and to seek their informed consent.

h. Provide details of any publications relating to the research.

81.1 Now I can only recall one research study. This was from around 1984. This involved Dr Sam Machin of the Department of Haematology, Middlesex Hospital. I think that this concerned about 15 patients. It related to assessing a new test for HIV. I think that patients were consented verbally by me (it was circa. 1984). As far as I can recall this study was not published rather presented to a haematology meeting.

82. Please provide the same details in relation to any epidemiological or similar studies in which you were involved, insofar as relevant to the Inquiry's Terms of Reference.

82.1 I have no relevant comments please see my response to 81.

83. Were patients involved in research studies without their express consent? If so, how and why did this occur?

83.1 I have no relevant comments please see my response to 81.

84. Was patient data (anonymised, de-identified or otherwise) used for the purpose of research or for any other purpose without their express consent? If so, what data was used and how and why did this occur?

84.1 I have no relevant comments please see my response to 81.

85. Was patient data (anonymised, de-identified or otherwise) shared with third parties (and if so, who) without their express consent? If so, how, and why did this occur, and what information was provided to whom?

85.1 I have no relevant comments please see my response to 81.

86. Please provide details of any articles or studies that you have published insofar as relevant to the Inquiry's Terms of Reference.

86.1 I have no relevant comments please see my response to 81.

Treatment of patients who had been infected with HIV and/or Hepatitis

87. How was the care and treatment of patients with HIV/AIDS managed at the Royal Liverpool Hospital (prior to your departure in mid-1985) and the Leeds Haemophilia Centre? In particular:

a. What steps were taken to arrange for, or refer patients for, specialist care?

b. What treatment options were offered over the years to those infected with HIV?

c. What information was provided to patients about the risks and benefits of specific treatments and about side effects?

87.1 As I can now recall in relation to HIV, no medicines were available until AZT in 1987 and so prior to that patients would have been managed with symptomatic support.

87.2 Generally I recall that in Leeds I had a good rapport with hepatology and infectious disease consultants and so although I was confident in initiating therapy, I could consult with colleagues if necessary. I followed the practice that I heard took place in Sheffield and would sit down with the infectious disease consultant once a month to review treatment programs. Complications such as infections would be treated in haematology. There was a similar practice for Hepatitis C with the help of hepatology using their protocols. Generally if complications occurred, or if a complete remission was not obtained, patients would be referred to hepatology for follow up. Therefore immediate referral to hepatology was not necessary which avoided patients having to go to several different clinics at a time.

88. What follow-up and/or ongoing monitoring was arranged in respect of patients who were infected with HIV?

88.1 I repeat my answer to 87. However, as far as I can recall these would have included a regular review clinic, regular blood test and a monthly review with the infectious disease consultant.

89. How was the care and treatment of patients with hepatitis B managed at the Royal Liverpool Hospital and the Leeds Haemophilia Centre? In particular:

a. What steps were taken to arrange for, or refer patients for, specialist care?

b. What treatment options were offered over the years?

c. What information was provided to patients about the risks and benefits of specific treatments and about side effects?

89.1 As far as I can now recall there were few patients with hepatitis B; there would be visits to the clinic and blood tests; if therapy was required there would be a referral to hepatology; there was no specific therapy for hepatitis B, and; I can no longer recall what advice was given to patients.

90. What follow-up and/or ongoing monitoring was arranged in respect of patients who were infected with hepatitis B?

90.1 Please see my response to question 89 above.

91. How was the care and treatment of patients with NANB hepatitis managed at the Royal Liverpool Hospital and the Leeds Haemophilia Centre? In particular:

a. What steps were taken to arrange for, or refer patients for, specialist care?

b. What treatment options were offered over the years?

c. What information was provided to patients about the risks and benefits of specific treatments and about side effects?

91.1 As far as I can now recall there was a difficulty in determining the cause of the condition which made treatment difficult. There would have been a referral to hepatology if liver function deteriorated. I can no longer recall what advice was given to patients.

92. How was the care and treatment of patients with hepatitis C managed at the Leeds Haemophilia Centre? In particular:

a. What steps were taken to arrange for, or refer patients for, specialist care?

b. What treatment options were offered over the years?

c. What information was provided to patients about the risks and benefits of specific treatments and about side effects?

92.1 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy.

92.2 However, as far as I can now recall the patients would be treated in haematology following hepatitis protocols if the patients responded well otherwise the patient would be referred to hepatology. As far as I can recall now the treatment would have been with interferon and ribavirin. I can no longer recall what advice was given to patients.

93. What follow-up and/or ongoing monitoring was arranged in respect of patients who were infected with hepatitis C?

93.1 I repeat my answer to 92. However, as far as I can recall this would have included a regular review clinic, hepatitis C monitoring, regular scans of the liver and discussion with and referral to hepatology when necessary.

94. What arrangements were made for the care and treatment of children infected with HIV or hepatitis? How did those arrangements differ (if at all) from the arrangements made for adults?

94.1 I did not treat children.

95. What, if any, arrangements were made to provide patients infected through blood products with counselling, psychological support, social work support and/or other support?

95.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what the specific arrangements were.

95.2 The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy.

However, as far as I can now recall at Leeds there was access to a social work resource organised by Sheila O'Rourke. There would have been counselling sessions and I believe that there were grieving clinics for the relatives of patients that died from around 1985, but I cannot recall how long these continued for. There was also the Skipton and Macfarlane Funds that offered a degree of financial support for patients and families.

96. Did the Royal Liverpool Hospital or the Leeds Haemophilia Centre receive funding from the Department of Health and Social Security or from any other source to help with the counselling of patients infected with HIV?

96.1 I do not know.

97. What, if any, difficulties did you/the Royal Liverpool Hospital and the Leeds Haemophilia Centre encounter in obtaining sufficient funding for the treatment of people who had been infected with HIV and/or hepatitis C?

97.1 I do not know.

98. What, if any, involvement did the Royal Liverpool Hospital and the Leeds Haemophilia Centre/you or your patients have with clinical trials in relation to treatments for HIV and/or hepatitis? Please provide full details.

98.1 As far as I can recall now, none.

Records

99. What was the policy of the Royal Liverpool Hospital and of the Leeds Haemophilia Centre in relation to recording information on death certificates when a patient had been infected with HIV or hepatitis?

99.1 As far as I can now recall I was rarely involved in death certificates. I think that I signed 2 in 40 years of practise and I cannot now recall anything about these certificates.

100. What were the retention policies of Royal Liverpool Hospital and the Leeds Haemophilia Centre in relation to medical records during the time you were practising there?

100.1 I do not know.

101. Did you maintain separate files for some or all patients? If so, why; where were those files located; and where are those files now?

101.1 As far as I can recall there would have been general hospital notes and then case notes regarding the haemophilia treatment kept in the haemophilia unit. I did not keep separate files for me.

102. Did you keep records or information (e.g. information being used for the purpose of research) about any of your patients at your home or anywhere other than the Royal Liverpool Hospital and the Leeds Haemophilia Centre? If so, why, what information and where is that information held now?

102.1 No.

103. Do you still hold records or information about any of your patients? If so, explain why and identify the records or information that you still hold.

103.1 No

Section 5: Self-sufficiency

104. In December 1974 the Department of Health announced additional funding with the primary aim of making the NHS self-sufficient in Factor VIII blood products within two to three years. The Inquiry recognises that you did not become a consultant haematologist until 1980. If you are able to respond, from your own knowledge, to the questions in this section please do so; if you are not, please say so.

a. When did you become aware of this announcement?

b. What did you understand the term "self-sufficiency" to mean? In particular, did you understand it to mean self-sufficiency in providing Factor VIII blood products prophylactically, or solely in response to bleeding incidents?

c. Did your understanding of what "self-sufficiency" meant change at any time? If so, when and why?

d. What was your understanding of how others defined "self-sufficiency"?

e. What if any role did you play, at any time, in any arrangements or initiatives designed to help achieve self-sufficiency?

104.1 I am unable to respond to this question as I know nothing of these matters, please seek this information from the appropriate organisations and groups.

105. How were estimates made of how much Factor VIII blood product would be required for use in England and Wales? In particular:

a. What was the role of the director of the Centre in making such estimates, and how did this change over time?

b. What was the role of UKHCDO and how did this change over time?

c. What assumptions would underpin the estimates (including assumptions as to how the blood products would be used)?

d. How would the estimate be made (e.g. by whom were they made, when and through what process)?

e. How were the estimates shared with other interested parties?

f. How did any of these processes change over time?

105.1 I am unable to respond to this question as I know nothing of these matters, please seek this information from the appropriate organisations and groups.

106. How were annual figures derived for how much Factor VIII blood product had been used over the course of a year?

a. What was the role of the director of the Centre in providing such figures, and how did this change over time?

b. What was the role of UKHCDO and how did this change over time?

c. How would the calculations be made (e.g. by whom were they made, when, through what process and using what data)?

d. How were those figures broken down geographically (e.g. by country, region or any other unit)?

e. How were the figures shared with other interested parties?

f. How did any of these processes change over time?

106.1 I am unable to respond to this question as I know nothing of these matters, please seek this information from the appropriate organisations and groups.

107. Were there significant differences between the estimates that were made and actual use? If so, why?

107.1 I am unable to respond to this question as I know nothing of these matters, please seek this information from the appropriate organisations and groups.

108. To what extent, if at all, did England and Wales (in your view) achieve self-sufficiency of Factor VIII blood products? Why (if this is your view) was self-sufficiency not achieved? Do you consider that more could have been done to achieve self-sufficiency and if so what?

108.1 I am unable to respond to this question as I know nothing of these matters, please seek this information from the appropriate organisations and groups.

109. Do you consider that there was a failure by haemophilia clinicians to provide timely and accurate estimates of future demand for Factor VIII blood products and/or a failure by haemophilia clinicians to identify the foreseeable increase in use of such products once they became available?

109.1 I am unable to respond to this question as I know nothing of these matters, please seek this information from the appropriate organisations and groups.

110. If self-sufficiency had been achieved in Factor VIII products, what, in your view, would have been the effect on the numbers of patients infected with (i) HBV, (ii) HCV, and (iii) HIV. Please comment on when self-sufficiency would have needed to be achieved (in your view) in order for any material difference to have been made in respect of each of these viruses.

110.1 I am unable to respond to this question as I know nothing of these matters, please seek this information from the appropriate organisations and groups.

Section 6: Blood Services and BPL

111. Please outline any interactions and dealings you had with the blood services, whether on a regional or national level, and/or with BPL during the time that you worked at the Royal Liverpool Hospital and the Leeds Haemophilia Centre.

111.1 As far as I can recall I had no interaction with blood transfusion services.

112. Please describe your involvement with BPL and/or the blood services and your role on any of its working parties, committees or groups. In answering this question please refer to [BPLL0004826] which lists you as a member of the Technical and Scientific Working Group on Viral Contamination of Blood Products from some point in 1981.

112.1 As far as I can now recall I was not on the working party and know nothing in relation to this question.

113. Do you know if any consideration was given to increasing production of cryoprecipitate, or producing a product with lower risk, in response to the risks associated with factor concentrates, and what, if any, involvement did you have with any blood service (regionally or nationally) and/or BPL in relation to this?

113.1 As far as I can recall I was not aware of plan to increase the production of cryoprecipitate or other product as described in the question and had no interaction with BPL as stated in answer to 111 above.

114. What, if any, discussions or meetings or interactions did you have with any blood service (regionally or nationally) and/or BPL in relation to:

a. the risk of infections with hepatitis from blood products;

b. the risk of infections with HIV/AIDS from blood products;

c. the steps to be taken to reduce the risk of infection?

114.1 None as far as I can recall.

115. What, if any, involvement did you have with any decisions or actions taken by any blood service (regional or national) and/or BPL in response to the risks arising from blood and blood products?

115.1 None as far as I can recall.

Section 7: UKHCDO

116. Please describe your involvement with UKHCDO (including any of its working parties, committees or groups).

116.1 As far as I can now recall I was a member of the organisation but not a member of any working party or group.

117. During the period that you were involved with UKHCDO, please outline:

117.1 I was at RLH between 35 and 40 years ago and so I cannot now recall what was happening at the time I was at RLH with any degree of detail or accuracy. The relevant time at Leeds is probably between 25 and 35 years ago and so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at this time when I was at Leeds with any degree of detail or accuracy. However, with those caveats as far as I can now recall:

a. The purpose, functions and responsibilities of UKHCDO, as you understood them.

117.2 In addition to being a forum for discussion it gave opinions of relevant areas of practice for haemophilia doctors. I cannot say whether it had any authority, but it was an effective group for collecting data.

b. The structure, composition and role of its various committees or working groups.

117.3 There appeared to be a member representing each geographical region. My personal view as far as I can now recall is that I did not think that the committees and working group within UKHCDO were very effective.

c. The relationships between UKHCDO and pharmaceutical companies.

117.4 I do not know.

d. How decisions were taken by UKHCDO.

117.5 As far as I can now recall I think that any decision was made through the chairman. I think that I may have voted on something once or twice but I cannot really remember now.

e. How information or advice was disseminated by UKHCDO and to whom.

117.6 I cannot now recall specifically. I think that we received a synopsis of each meeting which was approximately twice a year.

f. Any policies, guidance, actions or decisions of UKHCDO in which you were involved and which relate to:

- the importation, purchase and selection of blood products;

- the manufacture of blood products;

- self-sufficiency;

- alternative treatments to factor products for patients with bleeding disorders;

- the risks of infection associated with the use of blood products;

- the sharing of information about such risks with patients and/or their families;

- obtaining consent from patients for the testing and storage of their blood, for treatment and for research;

- heat treatment;

- other measures to reduce risk;

- vCJD exposure; and

- treatments for HIV and hepatitis C.

117.7 None that I can recall.

Section 8: Pharmaceutical companies/medical research/clinical trials

118. Have you ever:

a. provided advice or consultancy services to any pharmaceutical company involved in the manufacture and/or sale of blood products?

118.1 In relation to this question, I am being asked to recall events over 40 years which is virtually impossible with any degree of accuracy or specificity. The only situation I can recall now and only in the very broadest of terms is that Baxter pharmaceuticals asked a number of us to join them in an education day in London to talk about new hemophilia treatments or related area. I think that this may have been once or twice a year, but I cannot recall when or how many times this would have occurred.

b. received any pecuniary gain in return for performing an advisory/consultancy role for a pharmaceutical company involved in the manufacture or sale of blood products?

118.2 I cannot now recall specific amounts but this would have been a relatively modest sum of say £500 a day plus the expenses incurred in attending.

c. sat on any advisory panel, board, committee or similar body, of any pharmaceutical company involved in the manufacture or sale of blood products?

118.3 No, not that I can recall.

d. received any financial or non-financial incentives from pharmaceutical companies to use certain blood products?

118.4 No, not that I can recall.

e. received any funding to prescribe, supply, administer, recommend, buy or sell any blood product from a pharmaceutical company?

118.5 No, not that I can recall.

f. provided a pharmaceutical company with results from medical research studies that you have undertaken?

118.6 No, not that I can recall.

119. What regulations or requirements or guidelines were in place at the time concerning declaratory procedures for involvement with a pharmaceutical company? If you were so involved, did you follow these regulations, requirements and guidelines and what steps did you take?

119.1 In relation to this question, I am being asked to recall events and procedures over 40 years which is virtually impossible with any degree of accuracy or specificity, I cannot recall any guidelines now and so I cannot answer this question.

120. Have you ever undertaken medical research for or on behalf of a pharmaceutical company involved in the manufacture or sale of blood products? If so, please provide details. In particular please refer to the document [BAYP0000009_008] which suggests that at some point prior to 6 October 1986 you agreed to provide patients for a study of a Cutter product due to begin on 28October 1986. Did you enter patients into that study? If so, please provide details of the study including the consent process.

120.1 I am being asked about, inter alia, a specific study from 34 years ago. As I have said, I have been retired for 10 years now and am 77. As far as I can now recall I was not involved in the Cutter trial referred to in this question.

121. If you did receive funding from pharmaceutical companies for medical research, did you declare the fact that you were receiving funding and the source of the funding to your employing organisation?

121.1 As far as I can recall I did not receive funding from pharmaceutical companies for medical research.

Section 9: vCJD

122. When and in what circumstances did you become aware of the risks of transmission of vCJD associated with the use of blood and blood products?

122.1 vCJD is not something that I know a great deal about as it was not a disease that haemophiliacs contracted. Although I cannot recall with any degree of accuracy I may have first become aware of vCJD in the mid to late 1990s.

123. Did you have any involvement in decisions as to what information to provide to patients about vCJD? If so please answer the following questions:

a. What steps were taken and what processes were put in place at the Leeds Haemophilia Centre for informing patients about possible exposure to vCJD?

b. What steps were taken to tell patients of possible exposure to vCJD?

c. What steps were taken to provide information to patients about the risks of vCJD?

d. What steps were taken to arrange for counselling, support and/or advice to be offered to patients who were being informed that they might have been exposed to vCJD?

e. What measures were put in place, from a public health perspective, in relation to the care and treatment of patients?

123.1 Not that I can now recall and therefore I cannot answer a-e.

Section 10: The financial support schemes

124. What, if any, involvement or dealings did you have with the different trusts or funds (the Macfarlane Trust, the Eileen Trust, the Macfarlane and Eileen Trust, the Caxton Foundation, the Skipton Fund) which were set up to provide financial support to people who had been infected?

124.1 As far as I can now recall, and these recollections are only in the most general of terms, I had some involvement on behalf of patients in relation to:

- The Skipton fund for Hep C and liver disease. For this would have informed the fund so that payments could be arranged for patients anything that was required in addition to what I did would have been done by a social worker.
- The Macfarlane for Trust for HIV.

125. To what extent did the Leeds Haemophilia Centre and its staff (including you) inform patients about the different trusts and funds available?

125.1 I worked at Leeds for approximately 25 years between 10 and 35 years ago so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at the time I was at Leeds with any degree of detail or accuracy.

125.2 However, in general terms there would have been discussions with relevant patients about how these trusts operated but I cannot now recall the detail of what they would have been told.

126. Did the Leeds Haemophilia Centre have any policy or guidance for staff members to refer patients to the trusts and/or funds for support?

126.1 I worked at Leeds for approximately 25 years between 10 and 35 years ago so having retired ten years ago and now being 77 years of age I cannot now recall what was happening at the time I was at Leeds with any degree of detail or accuracy.

126.2 However, in general terms there would have been discussions with relevant patients about how these trusts operated but I cannot now recall the detail of what they would have been told.

127. What kind of information did you and/or the Leeds Haemophilia Centre provide to the trusts and funds about or on behalf of patients (a) for them to be accepted as eligible by the trust and/or fund, and (b) in respect of applications for assistance?

127.1 I cannot now recall specifics but I think in general terms the Skipton Fund would ask for blood test results, liver scan results and evidence of liver disease e.g. cirrhosis, liver cancer etc.

128. Were you and/or others at the Leeds Haemophilia Centre involved in the determination of whether a particular patient met the eligibility criteria for any trust or fund? If so, please explain who set the criteria, what those criteria were and how they were applied.

128.1 I cannot now recall specifics but I think in general terms the Skipton Fund set its own criteria. As far as I can recall it was seeking patients with significant liver disease such as cirrhosis or liver cancer etc. If the patient's condition progressed, additional or further payments could be made dependent upon subsequent scan results. I believe that it would be the Fund that would decide on the level of payments based on these scans.

129. Based on your own dealings with any of the trusts or funds and/or based on your knowledge of the experiences of your patients in relation to the trusts or funds, do you consider that the trusts and funds were well run? Do you consider that they achieved their purposes? Were there shortcomings or difficulties in the way in which they operated or in their dealings with beneficiaries and applicants for assistance?

129.1 My recollection as it is, is that Skipton Fund and the Macfarlane Trust were good.

Section 11: Other Issues

130. Please provide details of any complaints made about you (insofar as relevant to the Inquiry's Terms of Reference) to your employer, to the General Medical Council, to the Health Service Ombudsman or to any other body or organisation which has a responsibility to investigate complaints.

130.1 I cannot recall any at this time.

131. Please explain, in as much detail as you are able to, any other matters that you believe may be of relevance to the Infected Blood Inquiry, having regard to its Terms of Reference and to the current List of Issues.

131.1 None

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C

Dated 19 - 11 - 20

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