Witness Name: Pauline Sharp
Statement No.: WITN455801
Exhibits: none
Dated:

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAULINE SHARP

I, Pauline Sharp, will say as follows: -

Training and experience

1. My date of birth is GRO-C 1939. Between 1956 and 1958, I completed a pre-registration orthopaedic nursing certificate at the Royal Orthopaedic Hospital, Birmingham. In 1958, I started my general nurse training at Queen Elizabeth Hospital, Birmingham. I left in 1959 to get married. In 1971, I re-started my nurse training at St Luke's Hospital School of Nursing, Bradford. On 5th April 1973, I qualified as a state registered nurse. I gained my hospital certificate with honours and was awarded the gold medal.

2. From 1973 until approximately early 1976 I worked as a staff nurse on the care-of-the-elderly ward at St Luke's Hospital. During this time, I studied at Leeds Polytechnic for 2 years (day release). I was awarded a diploma in nursing by the University of London in October 1975.

3. During 1976 I was promoted to relief medical unit sister, and then appointed junior sister in dermatology. I was promoted to senior sister in 1977 or 78.

4. In 1979, the dermatology ward was moved from St Luke's Hospital to Ward 19, Bradford Royal Infirmary. This was a large, 30-bed ward with good facilities. Almost immediately, due to a bed shortage, we were taking medical sleep-outs, mainly haematology patients. I was supported at that time by Sister Jacques, senior sister for oncology and haematology, from whom I learned a lot about the care of these patients.

5. 4 haematology beds were formally allocated to my ward in 1982; often, more beds were used for haematology patients, by agreement with the dermatologists.

6. In the late 80s, following a staff reorganisation, I was appointed as Clinical Nurse Specialist (CNS) in haematology. I covered all haematology in-patients, the developing day-case unit based on the ward, and the haematology outpatients. In the early days, some haemophilia treatments were still given in the laboratory. I was also involved in the development of a comprehensive care team package with Dr Parapia, consultant haematologist, for haemophilia care. I visited Newcastle Haemophilia Centre on numerous occasions to observe and receive extra teaching in haemophilia and related bleeding disorders.

7. While I was at the centre, I attended 2 residential courses on counselling. In 1987, I completed ENB course 934, 'care and management of persons with acquired immune deficiency syndrome'.

8. Up to 1993, the ward continued to be a mixed dermatology and haematology unit. In 1993, the haematology unit moved to Ward 7, where it came to be known as the Annette Fox Haematology Ward. The dermatology unit returned to St Luke's Hospital.

9. I retired in October 1994. After my retirement, I was employed part-time by the Bradford Hospitals post-graduate centre. The UKCC 'Scope of Professional Practice' was being developed; my role was to work with others to develop a teaching and assessment programme of IV skills for nurses. I was also an NVQ assessor for care homes in North Yorkshire. I fully retired in 2001.

10. In 1982, I became a member of the local Haemophilia Society. On 12th July 1983, the Annette Fox Leukaemia Research Fund was inaugurated; it later became a registered charity. Despite its name, the fund provided (and provides) support to all haematological conditions including haemophilia. I was a founding member, and was the secretary for several years. I stood down in later in the 1980s, in view of a conflict of interest, since I was potentially in the position of applying for grants for equipment or patient support, and making decisions on the applications.

11. In about 1985, I became a member of the Haemophilia Nurses' Association (HNA), following meeting Peter Jones after he presented a paper on haemophilia care at the medical postgraduate centre in Bradford. In the late 80's, I became a member of the committee, and secretary. I remained in this position until my retirement in 1994.

12. I have never provided evidence or 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.

<u>The Bradford haemophilia centre</u>

13. The Bradford haemophilia centre was not a stand-alone centre but was an associate centre within the haematology department. While I worked there, I

was responsible for the care of patients with all haematological conditions, not just patients with haemophilia.

14. From the late 1970s until my appointment as CNS until the late 1980s, I was the senior sister on Ward 19. During this time, increasing numbers of haematological patients were treated on the ward, including patients with haemophilia. The ward had a large waiting area and a large treatment and examination area that we used for out-patient and day-patient care. In addition, a treatment and examination room was developed in the laboratory for some haemophilia care.

15. When haemophiliac patients were admitted to other wards, such as general-surgery or orthopaedic wards, staff from my ward would attend to administer their haemophilia treatments, and would have input into their care plans. While I was in this post, I gradually started to get involved with home and prophylactic treatment of haemophiliac patients.

16. From the late 1980s until my retirement in 1994, I was the CNS in haematology. My work covered the whole of haematology, not only haemophilia. We had about 100+ patients with inherited bleeding disorders. From memory, about 30 patients were diagnosed with haemophilia; 20 of these patients (16 adults, 4 children) had severe haemophilia A. Most of our patients were on home treatment over time. We held monthly haemostasis clinics.

17. The centre gained a good reputation; 5 patients asked to be treated in our centre, and were transferred from the centres in Leeds and Huddersfield.

18. As a member of the multi-disciplinary team, I was involved in all aspects of the care of haematology patients, from diagnosis through treatment and support. I was involved in administering prescribed treatments. I provided support and

teaching to patients receiving home treatments. I had a role in schools, training the teachers to provide appropriate support to pupils with haemophilia. I also provided support and advice to patients and their families, about living with haemophilia and related conditions.

19. When patients with haemophilia came into accident and emergency, they would usually ask for contact to be made with the haematology department; it was normal for me to attend, as I would when patients were admitted to other wards e.g. for surgery.

20. There were about 20 nurses on the haematology ward, including 2 ward sisters. They also covered the day unit. I provided clinical leadership to these nurses. I was also involved in recruitment of staff on the ward, and provided training and clinical supervision to staff.

21. I was involved in maintaining the policies and protocols in use in the haematology department, including the infection control manual, and the policy for storage and administration of blood products.

22. Other key members of staff were:

Dr Kay Hunt, consultant haematologist. In addition to her general role, she was clinical lead for sickle-cell anaemia, thalassaemia and related disorders.

Dr Liakat Parapia, consultant haematologist. In addition to his general role, he was clinical lead for haemophilia and related inherited bleeding disorders.

Dr Adrian Minford, consultant paediatrician.

Mr Hamilton, consultant orthopaedic surgeon, with a special interest in haemophilia and bleeding disorders.

Mr Hugh McCarthy, dental surgeon.

Andrea Breach, social worker and counsellor for haemophilia. She was appointed in the mid-1980s, and left in about 1989, and was not replaced. After she left, we would make social work referrals, as necessary, to the hospital social work department.

Jill Bond, physiotherapist.

Cheryl King, paediatric phlebotomist.

23. The doctors decided which blood products and medications to prescribe for all patients with inherited blood disorders. There were no non-medical prescribers in the department. Dr Parapia had the ultimate responsibility for prescribing blood products and made decisions about what products to order. Blood products were ordered by the haematology laboratory through the blood transfusion service.

24. I have been asked who was responsible for 'decisions as to what information to provide to patients about treatment, testing and/or diagnosis'. The answer is nobody. If I was qualified to answer a question, I would answer it. If not, I would refer it to a suitably qualified person. I would give accurate information to patients and answer patients' questions honestly. So far as I know, the same applied to every other member of the team.

Approach to the use of blood products

25. I first worked with haematology patients in the late 1970s, but cannot recall treating any haemophiliac patients until 1981. By that time, I think nearly all the patients diagnosed with severe haemophilia were receiving factor-concentrates. (This can be checked against the 'Oxford returns'—see below—if necessary.) I believe that there were protocols relating to the types of products to be used for the varying diagnoses. I was aware that factor-concentrates had brought about a huge improvement in our patients' quality of life and life-expectancy.

26. I remember cryoprecipitate being the treatment of choice for patients with Von Willebrand's disease. factor concentrates were used for severe haemophilia A as it was far more efficient. They were easier to make up, quicker, and could be used as a home-therapy. A child with a serious bleed would need a very high volume of cryoprecipate in order to raise the blood levels of factor-VIII sufficiently to achieve haemostasis. The high volume of fluid was potentially dangerous, and would take a long time to infuse. Delay in treating a bleed was also dangerous. We would not know how much factor-VIII had been given until we did post-infusion factor levels.

27. At a later date, heat-treated factor-concentrates became available. From memory, I think that all the concentrate we used from the mid-1980s was heat treated.

28. I recall one previously untreated child-patient, whom I will refer to as Patient A. He was born in 1984 and diagnosed with severe haemophilia in 1986. He had no family history of haemophilia, and his mother was not a carrier. He was treated with monoclate-P. I understood that he was the first person in the world to receive this product. I taught home therapy to the family. I am aware that he remains HIV and HBC negative, as he lives and works in GRO-C

29. Shortly before my retirement, recombinant factor-concentrates were starting to be used.

Approach to home treatment and prophylactic treatment

30. We would offer home treatment to all the adult haemophilia patients, and to the parents of all the child haemophilia patients. By the time, I starting working at the centre, many patients were already on home treatment.

31. The approach to home treatment and prophylaxis was to enable patients to have more control and independence. From memory, there were only about 2 patients who did not wish to use home treatment.

32. There was a strict written protocol in relation to home treatment. Over the years, I helped to update this protocol. The offer was made by the consultant, who would provide information. If the patient consented to home treatment, there would be an induction course carried out over a number of sessions which included home visits; usually I would carry out the induction course; sometimes the senior registrar would carry this out in my absence. Patients could withdraw at any time. Treatment packs were issued from and returned to the Haematology laboratory on a monthly basis.

33. I would train the patient (or the parent of a child patient) on the circumstances in which they should give home treatment, and how to administer the home treatment. We provided a home treatment pack, including a manual of how to store, reconstitute and administer the home treatment, and how to dispose of the products after use. An area in the home would be identified to prepare and carry out the therapy. We provided a suitable fridge for storage.

34. The patients would collect their home-therapy from the laboratory in a cool bag. We developed a 24-hour telephone contact service for patients to access in relation to bleeds and home-therapy problems. The ward and the laboratory were contact points.

35. The patients, and parents of child-patients, kept records of the treatments that they administered at home. They would record the date of treatment, the product administered, and the dose. I cannot recall whether they recorded the batch numbers or not. We would have a record of batch numbers and amounts of factor issued, in the central file kept in the laboratory. The home records were eventually filed with our records.

36. All haemophiliac patients, including those on home treatment, would be invited to the haemostasis clinic from time to time. The intervals would vary according to the severity of the condition.

37. The training that we gave to patients when starting home treatment would often include training on the circumstances in which they could administer factor-concentrates prophylactically. For example, if a patient was about to do something strenuous, or was going on a trip, he might administer factor-concentrate prophylactically. This would vary from patient to patient. Each patient understood his own needs.

38. The approach to home treatment and prophylactic treatment was essentially the same for children as for adults. All treatments were individual, based on the needs of the particular patient.

39. The laboratory staff completed the 'Oxford returns' every year. This was a record of the total number of units of each blood product used in the centre during the year, transcribed from the lab record; no individual patient was identified. The Oxford returns were sent to Rosemary Spooner in the Oxford Haemophilia Centre. I understand that this constituted an audit of blood products and provided useful information.

Policies

40. There were policies and procedures covering storage and administration of blood and blood products. There was very little change to these policies over time. I had no involvement with the ordering of blood products. I do not think that there was a written policy on ordering of blood products.

41. We also had Infection control policies which related to the handling of blood and disposal of sharps. The only adjustments I can recall were the

introduction of rubber gloves and some changes in skin cleansing in phlebotomy. These policies applied to all patients, not just those with known infections.

42. We had infection-control updates at regular intervals. These included updates, as necessary, on the risk of transmission of HBV, HCV and HIV.

Knowledge of risk

43. My understanding, from my basic nurse training, was that blood and body fluids were always treated as potentially hazardous substances. In the haematology unit, we would have regular updates about the known hazards.

Hepatitis B (HBV)

44. The transmission of HBV through blood and blood products was known. At the time when I started, most of the patients were known to be immune to HBV, either through previous exposure or because they had been vaccinated. With new patients, it was normal practice to screen for HBV, together with other conditions, and immunise the patient if not already immune. I cannot recall any new HBV infections while I was working at the centre.

45. Patients, and the parents of child-patients, were aware of the risk of transmission of HBV. Generally, they were extremely well-informed about their conditions and the risks of treatment.

Non-A non-B Hepatitis, or Hepatitis C

46. When I became involved in the care of haematology patients, I became aware of 'non-A non-B hepatitis'. It was known that something in our patient's blood, neither hepatitis A nor hepatitis B, caused an inflammation of the liver and elevated liver enzymes. It was not known whether this was a virus or other

infective organism. The effect on liver function was thought to be mild. At that time, 'non-A non-B hepatitis' was not thought to be a life-threatening condition.

47. Patients were given information about this in their consultations with the doctors, before starting treatment. Liver function tests were carried out routinely; if the results were abnormal, these were discussed with the patients. I believe that referral should be made to a liver specialist if there were concerns. However, I cannot remember any concerns that led to a referral while I was at the centre. I cannot comment on referrals after 1994.

48. Most of our patients and their relatives were members of the haemophilia society. They obtained information from the society bulletin, local and national meetings and seminars. Many of the patients, and the parents of child-patients, knew as much about non-A non-B hepatitis as we did. They often surprised me by the extent of their knowledge and understanding. They would ask very focussed questions about the results of their tests.

49. In about 1989 or 1990, the hepatitis C virus (HCV) was isolated. By that time, all our factor-concentrates were heat-treated. However, that had come too late. A majority of our haemophiliac patients tested positive for HCV. Most of these were already known to have HIV as well. Some patients with Von Willebrand disease tested positive for HCV, though only one of these had tested positive for HIV.

HIV/AIDS

50. When I first worked with haemophilia patients, I was vaguely aware of reports that a few haemophiliacs in the USA had developed unusual infections and conditions, similar to those affecting 'gay men', and that some had died, without a definitive diagnosis. Over the years, these reports accelerated. By

about 1983, we were aware that there was a rare but serious condition affecting a few haemophiliacs, mainly in the USA.

51. The majority of our patients were also vaguely aware of these cases, and would ask questions about them at the clinic. They were discussed in haemophilia society bulletins and meetings. At that time, this was not seen as a major issue, since there were very few cases. I remember that there was one known haemophiliac case in the UK, though there were more in America.

52. As time went on, scientists came to the conclusion that this was the result of an infection transmitted through blood products. The infection came to be known as acquired immune-deficiency syndrome—'AIDS'.

53. As we became aware of the risk of transmitting AIDS through blood products, we discussed this with our patients. I remember that most patients opted to continue treatment, understanding the risks but preferring to relieve their symptoms. Our patients were aware, as we were, that untreated haemophilia would severely shorten lives.

54. Some time, in the mid-1980s, urgent information was received, informing us that certain batch-numbers of factor-concentrate were thought to be infected. From memory, the majority of our patients were receiving products with the identified batch-numbers. We immediately withdrew the factor concentrate from use. We visited homes and took the products away. For a short period of time (weeks, not months) all home-treatment ceased. All treatment was given at the centre. The decisions relating to the products used at this time were made by Dr Parapia.

55. Not long afterwards, heat-treated products became available. These were thought to carry a lower risk of infection, though there was no certainty about this.

56. At that time, Patient A was previously untreated. Dr Parapia was able to obtain monoclate-P to treat him, as set out above. As far as I recall, all our other patients chose to continue to have treatment with factor-concentrates, since there was no good alternative.

57. Up to then, factor-VIII had, I believe, occasionally been given to patients with Von Willebrand disease, though it was not the treatment of choice. At about that time, it became our policy not to give factor-VIII to patients with Von Willebrand disease in any circumstances.

58. By that time, we knew that there were 3 groups at risk of this illness: gay men, intravenous drug users and haemophiliacs. We became aware of the risk that our patients might transmit the infection to sexual partners. Therefore, we started to give safe-sex advice to our patients.

59. When a test for HIV infection was introduced, all our haemophiliac patients were offered the test. All but one of the haemophiliac patients who had been receiving factor-concentrates tested positive. One of our patients with Von Willebrand's disease tested positive. When we offered tests to our patients' partners, none of these tested positive at that time.

60. At a later date, a young patient with severe haemophilia revealed that he had had unprotected sex; sadly his partner then tested positive. He had received counselling on 'safe sex' on a number of occasions. A patient from another area moved to our area. He and his partner had already tested positive when he came to us.

Commercial and NHS blood products

61. Some factor-concentrates were manufactured at the BPL from blood donated to the UK blood transfusion service. However, it appeared that there was not

enough of the BPL factor-concentrate for all the haemophiliac patients in the UK. The UK therefore needed to import factor-concentrate from abroad. At that time, it was thought that we could not achieve the number of blood donors required, and that the BPL laboratory at Elstree had insufficient manufacturing capacity.

62. Since the 1970s, staff in the haemophilia centres had been lobbying the government to achieve self-sufficiency in blood products. When we became aware of the risk of AIDS, then the lobbying became more intense.

63. In the early 1980s, there was a growing suspicion within the haemophilia community, including patients, that imported factor-concentrates might be more likely to transmit infection than BPL factor-concentrates. In our centre, we discussed this openly with patients. Our medical team, led by Dr Parapia, decided which blood products to order. From memory, I believe that all the factor-concentrate that we used from the mid-1980's was heat treated.

Training and advice on information to give to patients

64. I have been asked whether any training or advice was given to staff at the centre on what information to give to patients about the risks of infection. The answer is no. As stated above, we received updates at intervals about what the risks were. We would pass this information on to patients. I would answer patients' questions as fully as I could, giving accurate information, to the best of my knowledge at the time. Most of our patients were well-informed about their conditions, and the potential risks of treatment.

Testing, treatment and care of patients

Consent to treatment

65. Whenever a new patient with an inherited blood disorder required treatment, and whenever an existing patient's treatment was changed, there would be a discussion with the doctor. For adult patients, the discussion was usually with Dr Parapia, or his senior registrar. I was usually present.

66. For child patients, the discussion was usually with Dr Minford. From about the mid-1980s, there were joint clinics for adult and child patients. Dr Minford and Dr Parapia would often see the parents of child-patients together. Children of sufficient understanding were involved in the discussion.

67. Child-patients were transferred to the adult setting in their late teens. Dr Minford held joint clinics with Dr Parapia to manage the transition. I was present at these clinics.

68. The discussion would always include information about the risks of infection from treatment. The patient or parent had the opportunity to ask questions about these risks. The information would be in line with the state of knowledge that the doctors had at the time. For example, in the early 1980s, they had very limited knowledge of HCV or HIV.

69. From about the time that we became aware of the risk of HIV, there would be a discussion of the use of cryoprecipitate, in certain circumstances, as an alternative to factor-concentrates. However, for most kinds of bleed, this was not a viable alternative, and was not acceptable to the patient.

70. I have been asked to what extent decisions about treatment were taken by the doctors rather than the patients. Most patients, in my experience, were extremely well-informed about the condition and treatments, and participated

in all decision making. While the doctor gave advice, the decision was the patient's.

71. A full discussion and training was given before commencing home treatment, as set out above.

72. Consent was given verbally. While I was at the centre, we never used written consent forms to record consent to treatment.

Training in obtaining consent

73. I was never given any training or instruction at the centre on obtaining consent to treatment. However, I was aware of the need for consent from my general nurse training. After I qualified as a nurse, I completed a diploma in nursing. Ethical questions, including consent, were discussed in the course.

74. While working at the centre, I attended 2 residential courses on counselling and completed ENB 934 'care and management of persons with acquired immune deficiency syndrome'. These courses included discussion about obtaining consent to treatment and testing.

75. At the centre, the doctors would prescribe the treatment, and would obtain initial consent to treatment. When I administered treatment, I would confirm that the patient understood the treatment. At that time, I would answer any questions that the patient might have.

76. I had numerous discussions with patients about the risks of infection through factor-concentrates, and the risk of passing this on to others. I would answer the patients' questions to the best of my knowledge.

77. I have been asked whether I was ever told to withhold information from a patient or patients about risks, or treatment, or testing, or diagnosis, or their condition. The answer is no. I would tell patients as much as I knew, and answer their questions fully and frankly.

Routine blood tests

78. We would do routine blood tests on all haemophilia patients at the clinics. The tests would include full blood count, coagulation tests and liver function tests. The patients attending the clinics were very familiar with the purpose of these tests. Any abnormal results would be discussed with the patients at the same clinic.

79. The blood was usually taken in the phlebotomy department, which was attached to the laboratory. When the patient came into the clinic, they knew to go to the laboratory first, for these tests.

80. Occasionally, I took blood myself for routine tests. If the patients had any questions, I would answer them. However, the patients were very familiar with the routine blood tests that they were having.

Liver function tests (LFTs)

81. LFT's were part of the routine blood tests. As such, blood for these was usually taken in the phlebotomy department just before the clinic. If the results were abnormal, these were discussed with the patient at the clinic.

82. The possible causes of abnormal LFTs were discussed with the patients. There were a number of factors that could give rise to abnormal LFTs. These included other medical conditions, side effects of medical treatment, lifestyle factors unrelated to haemophilia, or the condition that we knew as hepatitis non-A non-B.

Tests for HBV, HIV and HCV

83. We would routinely test all new patients for HBV immunity. If new patients were not immune already, we offered them immunisation. I do not remember any new patients at the centre who had active HBV infection.

84. When an HIV test (then called an 'HTLV-III antibody test') became available, this was offered to all haemophiliac patients. By that time, the great majority of our adult patients, and the parents of our child patients, were aware of HIV. I remember several patients asking to have a test for HIV as soon as one became available.

85. There was no HCV test available until the early 1990s, not long before I retired. When available, the test was offered to all patients who had received blood products. Most of the adult haemophiliac patients, and the parents of child patients, were aware of HCV. At this time, I do not think that either clinicians or patients realised how severe were the long-term consequences of HCV infection.

86. The tests for HIV and HCV were not routine. The blood was usually taken by nursing staff, not by the phlebotomist.

Consent to blood tests

87. I have been asked whether any training, advice or instruction was provided to me in relation to obtaining patient consent to blood testing.

88. As stated above, there was discussion about obtaining consent to treatment and testing in the ENB 934 course, 'care and management of persons with acquired immune deficiency syndrome', and in my counselling courses.

89. At our team meetings, we discussed HCV and HIV, and information that would be required for the patients to give informed consent to the blood tests. At some team meetings, we had input from the infection control team.

90. When I took blood for testing, I would satisfy myself that the patient understood why I was taking the blood and what tests would be carried out. As we became aware of the possible social consequences of a positive HIV test, such as the consequences for insurance, we would discuss this with the patients before taking blood for the test. I do not remember any patients refusing a test after this discussion. Counselling was offered to all patients having the test. I would make a record in the patient's notes that the patient had agreed to have a test.

Informing patients of test results for HIV and HCV

91. We would arrange a time to give test results in person, soon after we received them. Relatives were welcomed if the patient wished them to be present. In most cases, Dr Parapia would give the results to the adult patients in person. I was usually with him. Dr Parapia and Dr Minford would usually give the results on child patients together.

92. Our policy was not generally to give test results over the telephone. In the rare cases where distance was an issue, a telephone consultation was arranged with a personal follow-up.

93. After a positive test, and with the consent of the patient, a test would be offered to partners. The process of obtaining consent and informing them of the results was the same.

94. This procedure equally applied to HIV and HCV testing.

Counselling and support

95. By the time that they were tested, our patients had already been given advice about sexual relations and prevention of cross-infection.

96. At that time, Andrea Breach was already employed as a hospital social worker, but not specifically in our department. As a result of the HIV tests, she became the dedicated social worker and counsellor for haemophilia and related disorders. She provided support to the patients, as did all staff in the department. We had known these patients for years, and supported the patients as a team.

97. Support was also offered to the families of infected patients. Both Andrea and I did home visits. Many patients would attend the centre with their families.

98. Andrea left the Trust in the early 1990s, and was not replaced by a dedicated social worker, though we did have access to social work support from the hospital social work department. I had been trained in counselling by then, and could provide counselling to patients who wished for this.

99. After Andrea left, the Trust also appointed 2 HIV counsellors, based at the genito-urinary clinic, with a remit to cover the haematology unit. Most of our patients preferred to rely on the support of staff in the department. One of the reasons for this was that some of our patients blamed the homosexual population for their condition.

Treatment of patients with HBV and HCV

100. To the best of my recollection, no patient at the centre required treatment for HBV while I was there.

101. To the best of my recollection, none of the patients who tested positive for HCV had serious liver damage during the time that I was at the centre. I do not recall anyone becoming seriously ill with HCV, or dying of HCV, while I was at the centre. I do not have a clear memory of any patients receiving treatment for HCV at the centre while I was there.

Treatment of patients with HIV

102. Patients who were HIV-positive would not be treated for their HIV unless and until they had symptoms. We gave advice about safe sex, and about all aspects of infection control. We provided emotional support to patients and families as set out above.

103. There was a great deal of stigma attached to HIV. The transmission of HIV was not fully understood by the public. It was widely seen as transmissible through ordinary social contact.

104. At about that time, haemophilia became associated with AIDS; to many members of the public; 'AIDS' was a dirty word. This resulted in many of our patients becoming socially isolated. Sometimes this even applied to staff working with haemophiliacs. We sometimes found that other staff were avoiding us.

105. The schools were not informed if a child was HIV positive. However, once it became known at school that a child had haemophilia, there were some who were reluctant to keep the child in the school. I used to visit the schools, accompanied by staff from the public health department at Bradford City Council, in order to give correct information.

106. The other groups affected were mainly gay men and intravenous drug users. Some of our patients blamed the other groups of giving them their infections.

Others, for example mothers, felt guilt in passing on haemophilia to their sons, and also for delivering home therapy to their sons.

107. I do remember one occasion when an HIV positive patient had a fracture and a serious bleed. He went to Accident and Emergency (A+E). The orthopaedic doctor on call in A+E did not want to treat him, because he was HIV positive. I was called to A+E. I called the haematological registrar; we treated the bleed. Subsequently, the patient did receive appropriate orthopaedic treatment under Mr Hamilton.

108. This incident stands out because it was exceptional. Generally, patients with HCV and HIV were not treated differently from other patients in the department. The policies for prevention of cross-infection were the same for all patients—later known as 'universal precautions'. The only policies that were different were in relation to death of a patient; these were put into place by the public health consultant and team.

109. While I was at the centre, many of our HIV-positive patients began to develop symptoms associated with AIDS. They continued to be cared for as in- or out-patients under the care of Dr Parapia and Dr Minford, since there was no developed alternative service to refer to. Some of the care packages included the drugs AZT, ganciclovir and pentamidine.

110. I was usual present at the clinic appointments where HIV treatments were prescribed. The treatment of HIV could not be separated from the treatment of haemophilia; there was a single treatment-plan that included the patient's haemophilia and HIV treatment. I was involved with all aspects of the patient's care.

111. We provided inpatient treatment as necessary on the haematology ward. I was not usually physically involved in in-patient treatment, which was

administered by the ward staff. However, I was always aware of how patients were getting on, and would visit them on the ward. On the haematology ward, we were very experienced at protecting patients from opportunistic infections, because we needed to do so for patients receiving chemotherapy. We subsequently received GP-referrals of patients from other at-risk groups; these patients were also treated in the haematology department.

112. AIDS affected different patients in different ways. One of our patients became severely demented; he was quite a young man. Other patients became very depressed. A number of patients developed pneumocystis carinii pneumonia (PCP) and other opportunistic infections, including severe cold sores.

113. We had at least 12 deaths from AIDS while I was at the centre, of which 3 were children, and one was the female partner of an adult patient. This was devastating to all concerned. In a haematological department, we were dealing with many life-threatening conditions, such as leukaemia, lymphomas and myelomas, but we used to think of our haemophilia treatments as very effective, and enabling our patients to lead a normal life. It was terrible to think that we had unintentionally caused their illness.

Research

114. So far as I know, no research took place in the Bradford Haemophilia Centre.

115. I recall the term 'previously untreated patient' being used to describe Patient A. As far as I know, he was the first patient in the world to be treated with monoclate. He still attends the centre. He is a very healthy young man, free from infections and joint problems.

vCJD

116. I retired in 1994. I had no knowledge of vCJD, or of the risks of transmission of vCJD with the use of blood and blood products.

Other issues

Financial support

117. I was aware of the Macfarlane Trust, which was set up in 1988 to provide financial support to people infected with HIV through blood products. All the patients were given information in relation to the Macfarlane Trust. This was publicised at the haemophilia society; the Macfarlane Trust provided written information that we passed on to patients.

118. Andrea Breach, the social worker helped patients to complete the application forms to the trust. When Andrea left, I would do this. We would provide statements in support of applications.

119. I remember patients receiving one-off payments of £20,000. They could make application for other grants, such as a grant for central heating.

Records

120. I have been asked about the retention policies regarding medical records. I do not know what the policies were. My understanding was that records were retained for a certain period of time after death.

121. There was a treatment card kept to record all treatments with blood and blood products. This was kept separate from the patient notes. When a patient attended for treatment, we would fill in details of the treatment on the card, and return it to the laboratory. The treatment cards for current patients were

kept in the laboratory. The cards were filed with the patient's notes when the patient transferred to another unit, or died.

Discussions with senior clinicians

122. I have been asked whether I have had any discussion with senior clinicians at Bradford haemophilia centre about any issues that may be relevant to the inquiry. Dr Parapia informed me that he had responded to a patient statement and had named me in his response. I have since read Dr Parapia's statement. This has not influenced the contents of my statement in any way.

The contents of this statement are true to the best of my knowledge and belief.

Signed GRO-C

Dated: 19th November 2020.