Witness Name: Sheila Hayden
Statement No.: WITN5722001
Exhibits: None
Dated: 1st November 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHEILA HAYDEN

I, Sheila Hayden, will say as follows: -

1. My date of birth is GRO-C 1961. My address is known to the Inquiry.

Qualifications

2. In 1982, I qualified as a registered nurse, learning disability. In 1984, I qualified as a registered general nurse. In 1989, I completed the English National Board (ENB) course 237, oncology care. In 2001, I completed an MSc in nursing (advanced practice). In 2002, I completed ENB course UO1, the essentials of haemophilia care.

My career

3. Between 1982 and 1983, I worked as a staff nurse on the children and adolescent unit at St. Joseph's Hospital Rosewell, Midlothian, supporting young people with learning disabilities and other health problems.

4. Between February 1983 and August 1984, I completed a post-registration course in general nursing at Victoria Hospital, Fife. Between August 1984 and

August 1985, I worked as a staff nurse at the Royal Infirmary of Edinburgh, first in care of the elderly, then on the intensive care unit.

5. I then moved to London. Between September 1985 and November 1986, I was a staff nurse on the bone marrow transplant unit at St Bartholomew's Hospital. Between December 1986 and June 1987, I was a staff nurse on the oncology ward at University College Hospital. Between September 1987 and March 1988, I was a staff nurse in outpatients at Middlesex Hospital. Between April 1988 and January 1989, I completed the post-registration oncology course at St Bartholomew's Hospital.

6. From 1989 to 1991, I was nursing sister in haemophilia and haemoglobinopathies at the Royal London Hospital. Between January and July 1992, I had periods of sick leave due to antenatal complications. Between GRO-C 1992 and the spring of 1993, I was on maternity leave and I returned to post 3 days per week.

7. In 1993, I was appointed clinical nurse specialist in haemophilia at the Royal London Hospital. I was part time, 3 days a week. From GRO-C to November 1995, I was on maternity leave. I then returned with reduced hours, 2 days per week. Between 1998 and 2000, I completed a master's degree in nursing. During this time, I worked 1 day a week in my clinical role, and 1 day a week studying for my degree.

8. In 2000, I was promoted to 'senior clinical nurse specialist'. I continued to work part time, 2 days a week. I left this post in 2003.

9. In 2003, I was appointed lecturer in clinical skills at the medical school, St George's University of London, a post I held until 2008. Between 2008 and 2010 I held a part-time tutor post at UCL medical school. From 2010 to 2014, I worked as a lecturer in clinical and communication skills at Queen Mary University of London. In about 2015, I was appointed on a 6-month contract

as a part-time lecturer in clinical skills teaching on the master's degree course in nursing at City University, London.

10. Since 2015, I work as a sessional tutor, examiner, and seminar-leader at St George's University of London and Kings College London medical schools.

11. In 2019, I returned to a nursing role as a nurse volunteer with a refugee and asylum seekers' charity, 'Doctors of the World'. I provide patient advocacy and clinical support to patients attending their East London clinic, and have offered remote advice and support since the start of the Covid-19 pandemic in 2020.

12. Since March 2021, I have also been working as a part-time nurse screener and vaccinator in Covid-19 vaccination clinics in Peckham and Dulwich.

Membership of associations and working parties

13. Between April 1995 and June 1996, I was an honorary officer of the Royal College of Nursing Haemophilia Nurses' Association.

Inquiries and litigation

14. I have never provided any 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.

The haemophilia centre at the Royal London Hospital

15. I held 3 roles at the haemophilia centre at Royal London Hospital: nursing sister between 1989 and 1991; clinical nurse specialist, part time, between 1993 and 2000; senior clinical nurse specialist, part time, between 2000 and 2003.

16. My part-time hours varied between 1 and 3 days per week, as set out above. I had periods of sick leave and maternity leave in 1992–3 and 1995, as set out above.

My responsibilities as nursing sister

17. When I started as a nursing sister in 1989, I was the only hospital-based nurse working with the haemophilia patients at the Royal London Hospital. We shared a community haemophilia nurse, Wanda Little, who also supported patients from the Royal Free Hospital.

18. I was responsible for assessing patients who attended the day-ward with mild bleeding episodes, or who were requiring dental or other procedures; administering and documenting the treatment; advising on follow-up and subsequent treatment and support. I carried a bleep and was usually the first point of contact during the day for patients who experienced a bleed or needed advice.

19. My other duties included: patient education, support, advice and advocacy, provision of training and support to patients and their families in the administration of home treatment, support to patients who were infected with and receiving treatment for blood-borne viruses.

20. As set out above, I had periods of sick and maternity leave between January 1992 and the spring of 1993. To the best of my knowledge, there was no haemophilia nurse covering my role during that time. I think that junior doctors would have carried out the majority of my duties in the hospital. The community haemophilia nurse continued her role supporting patients in the community.

My responsibilities as clinical nurse specialist

21. The role of H-grade clinical nurse specialist was created when I returned from maternity leave. I worked in this role 3 days a week. At about that time, another nurse was appointed to work on the unit. To the best of my memory, she was a G-grade sister. A third nurse had joined the team by about 1995–6.

22. As clinical nurse specialist, I was involved in training new members of the team, including nurses and junior doctors. I supported and trained staff on other wards of the hospital. I also trained staff in associate haemophilia centres, although this was most usually done by the community haemophilia nurse. I specifically recall training staff at Chelmsford Hospital. I cannot remember the other centres.

23. The bulk of my time was still spent in patient contact, i.e. assessing patients, training patients for home treatment and administering treatment as set out above.

My responsibilities as senior clinical nurse specialist

24. The post of senior clinical nurse specialist was created in 2000. At this time, there were 2 other clinical nurse specialists in the centre.

25. In addition to my responsibilities as clinical nurse specialist, I had some line management responsibilities for the other clinical nurse specialists. The bulk of my time was still spent in direct patient contact, as above.

Other staff

26. At the time of my appointment, the Haemophilia Centre was part of the Department of Haematology, which was headed up by Professor Jenkins. The Haemophilia Centre director was Dr Brian Colvin. Other consultant

haematologists were Dr Adrian Newland and Dr Louise Tillyer; they may have provided consultant cover in Dr Colvin's absence.

27. Junior doctors, i.e. senior registrars and registrars in haematology, were also assigned to work in the centre. There were a number of senior registrars over the years. Those whose names I recall are Dr Lydia Jones, Dr Steve Kelsey, Dr Jamie Kavanagh and Dr Mary Cahill.

28. Our centre was described as a Comprehensive Care Centre. A number of different specialists in the multidisciplinary team were involved in the care of the patients.

29. There were 2 consultant paediatricians, Dr Snodgrass and Dr Harris, who supported Dr Colvin in the provision of paediatric care to children with haemophilia. Junior doctors in paediatrics were also involved in the care of the children admitted to the paediatric ward. There was also a paediatric ward nurse who specialised in haematology who supported us in caring for children with haemophilia and von Willebrand's disease. I cannot recall her name.

30. There was a consultant orthopaedic surgeon and a consultant rheumatologist, Dr Barnes who saw our patients with haemophilia. There was a consultant paediatric dental surgeon, Dr Davenport, who treated children with haemophilia. I cannot remember the names of the dentists who looked after the adult patients. Patients with liver disease were cared for by a consultant gastroenterologist, Dr Swain. Other specialists who supported these patients included ENT, respiratory and dermatology consultants.

31. Designated physiotherapists from the department of physiotherapy in the hospital provided care and treatment to our patients. Patients had support from a paediatric social worker, an adult social worker and an HIV social worker who were based in the Hospital's social work department.

32. The care of patients with haemophilia who were HIV positive was led by Dr Colvin with specialist consultant input from Dr Skinner and her team in the Hospital's Ambrose King Centre which provided care and support for patients with HIV in the Hospital. Dr Colvin and Dr Skinner saw patients with haemophilia and HIV, in a joint clinic.

33. The nursing team at the centre consisted of 2 clinical nurse specialists and me. There was a community haemophilia sister, Wanda Little, who visited patients in the community.

34. Dr Colvin had a very hands-on role in seeing patients during the working day and frequently saw patients out of hours if that was required. There was also an on-call system whereby Dr Colvin's senior registrar or registrar assigned to haemophilia care would be contacted by any hospital doctor seeing a haemophilia patient out of hours.

Decisions as to the selection and purchase of blood products

35. During my period of employment, decisions in relation to the selection and purchase of blood products were led by Dr Colvin. He held regular meetings with hospital managers, finance managers and pharmacy staff. A nurse would attend these meetings—either me or a haemophilia nurse colleague. The haematology registrar would also attend.

Approach to the use of blood products

36. Dr Colvin decided on the appropriate treatment for each patient. I believe that he would prescribe in accordance with the guidelines provided by the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) and government recommendations. I do not recall any other policies or standard operating procedures for the prescription of blood products. I believe that the UKHCDO guidelines changed over time, to reflect the development of new treatments.

37. In 1994–95, a protocol was agreed between Dr Colvin and the nursing staff, under which nurses could administer urgent haemophilia treatment to patient-groups in hospital or the community without waiting for a specific prescription to be written. In 1995, we published a paper called *Implementation of a nurse-practitioner policy for the requisition and administration of drugs in a haemophilia comprehensive centre*, in the first edition of a journal called *Haemophilia*.

38. When I started work at the centre in 1989, children and adults with severe or moderately severe haemophilia, or severe von Willebrand's disease, usually received heat-treated factor VIII and factor IX treatments, obtained from the bio-products laboratory (BPL). Wherever possible, patients with von Willebrand's disease, or mild to moderate haemophilia, received DDAVP.

39. When recombinant factor VIII and IX treatments became available to us, Dr Colvin gave all children receiving factor VIII or factor IX treatment the recombinant treatment. I cannot recall the specific year the treatment was first used but it would be documented in patients' records and on their treatment forms. Recombinant treatment may also have been given to new, mildly-affected adult patients that had not previously received blood products or concentrates, but this recollection would need to be checked with the treatment records.

40. I recall that there was a problem with the supply of recombinant factor VIII around the late-1990s. The issue was communicated to patients and parents as soon as we became aware. Dr Colvin arranged a meeting of patients and parents to discuss the implications for treatment and to propose a way forward. To the best of my memory, we managed to maintain a sufficient supply of recombinant treatment and avoided having to give blood products to children during this period.

41. To the best of my memory, adults on the home treatment programme, and those attending or admitted to hospital for treatment, continued to receive NHS/BPL heat-treated factor VIII and IX throughout my time at the hospital.

Approach to home and prophylactic treatment

42. To the best of my memory, all patients with severe haemophilia A or B, or severe von Willebrand's disease, were on the home treatment programme. All children with haemophilia on the home treatment programme received prophylactic treatment. Some severely affected adult patients also had prophylactic treatment, although others took their treatment as required.

43. The nursing team in the hospital, together with the community haemophilia nurse, Wanda Little, managed the training and support of the patients receiving home treatment. Home-treatment patients attended regular hospital clinics for monitoring and support.

44. Regular evening support meetings were also held in the homes of patients, at which groups of patients, parents, and families came together for mutual support. These meetings were usually attended by the community nurse and me; on occasion, Dr Colvin attended.

45. This approach to home treatment continued during my time in post.

Decisions as to what information to give to patients

46. When patients asked me questions about treatment, testing or diagnosis, I would answer honestly, to the best of my knowledge. Nobody told me what to say or not to say. If I did not know the answer, I would ask someone with a greater level of knowledge, such as Dr Colvin, to answer the question.

47. Many patients with haemophilia were well informed about their condition.

48. Written patient-information leaflets were produced by the Haemophilia Society. We would give them to patients. Many of our patients were members of the Haemophilia Society.

49. I have been asked if I was ever told to withhold information from a patient about risks, or treatment, or testing, or diagnosis, or the patient's condition. The answer is no.

Knowledge of risk

50. Through my previous oncology training and my work as a staff nurse in other hospitals, I was aware that patients had been infected with hepatitis B and HIV from blood and blood-products.

51. I learned about non-A non-B hepatitis when I joined the haemophilia centre. The hepatitis-C virus was identified at around that time. I also learned more about HIV infection in haemophilia at that time.

52. I received training and education from the community haemophilia nurse and Dr Colvin, both of whom were experienced specialist clinicians and enthusiastic teachers. I also had the opportunity to visit other London haemophilia centres, the Haemophilia Society and the Macfarlane Trust. As time went on, I attended conferences and meetings that were organised by the Haemophilia Nurses' Association (HNA), the Royal College of Physicians (RCP) and the UKHCDO.

53. My knowledge and understanding developed over time, through clinical experience, supporting affected individuals and their families and reading research literature.

54. I understood that, since 1985, there had been a relatively low risk of viral transmission associated with the use of blood and blood products, due to the

commencement of donor selection and screening, and because of the heat-treatment process for factor concentrates.

Commercial and NHS blood products

55. I understood that, since about 1985, the NHS blood and blood products were relatively safe and carried a low risk of transmitting viruses. I cannot remember ever treating patients with commercially supplied blood or blood products, but understood that commercial products were also relatively safe by this time.

Training and advice on communicating risk to patients

56. Primarily my training was gained experientially through working closely with Dr Colvin particularly by participating in clinics where Dr Colvin advised patients of the risks of infection. Experience gained discussing these risks with patients further improved my communication skills.

Reducing the risk of infection

57. Whenever possible, DDAVP was used for the treatment of mildly and moderately affected patients. The decision to use heat-treated products, which pre-dated my starting date, meant that, as far as I can recall, no patients treated at the centre became infected with blood-borne viruses during my time working there. The purchase by the hospital of recombinant products for children, when they became available in the 1990's, further reduced the potential risks of infection from blood products.

Treatment for haemophilia

58. New patients would usually be referred to our centre by a GP, paediatrician or A&E doctor, typically after a history of attending A&E with bruising or bleeding. The diagnosis would be made following analysis of blood samples.

Any new referral with symptoms of bleeding or bruising would be seen as a matter of urgency. All new patients referred were seen promptly by Dr Colvin.

59. Before starting treatment, Dr Colvin would have a discussion with the patients and parents about the treatment options; this discussion would be documented in the notes. Decisions about treatment were made after any questions or concerns had been addressed. A member of the nursing staff would normally be present at this discussion. A junior doctor would often also attend.

60. Children and adults with a severe bleeding disorder were advised of the need for treatment with factor concentrates, or the recombinant products, when available.

61. For individuals with milder factor VIII deficiency, or mild Von Willebrand's disease, treatment with DDAVP was usually advised. However, they were advised that a factor-concentrate may be required for preoperative treatment or a serious bleeding episode.

62. If a patient declined treatment, for example, because of religious beliefs, Dr Colvin always took the time to communicate with and support the patient, whilst ensuring that the patient understood the potential consequences of not accepting treatment if it became necessary.

63. Patients and parents were made aware of the potential risk of transmission of viruses and infections from all products derived from blood donations, including the recombinant products containing human albumin. It was explained that, because of the processes used, the risks were low.

64. This information was initially given by Dr Colvin. However, nursing staff would often be asked questions, and would need to repeat or reiterate the information already provided.

65. Dr Colvin would often recommend a book for patients called *Living with Haemophilia*. We would offer to lend a copy of this book to patients.

66. We would recommend to new patients that they consider joining the Haemophilia Society, who would provide them with further information.

Starting home treatment

67. Dr Colvin met with patients commencing home treatment for an explanation of the process and details about the dose and regimen.

68. The patients' training took place either in the hospital or in the community. All adult patients receiving home treatment were already on the home treatment programme when I arrived. I was therefore only involved in training new parents of children. Parents were informed about the prophylactic dose and frequency required for their child, about documenting the treatment (including batch numbers) and returning the treatment forms to the Hospital. Patients were also taught about infection control measures and disposal of sharps. They were advised how to contact the centre staff for advice during the day or at night and what to do if their child had a bleed. New patients and their parents were also informed about the need for hepatitis B vaccination.

69. The ongoing support for patients and families was provided by the community haemophilia nurse, by patient support groups, and by the Haemophilia Society.

Blood testing

70. It was usual to take blood samples from patients when they attended the hospital. Several different blood tests were taken depending on the patients' circumstances. When I took blood from patients, I informed the patient/guardian what the bloods tests were for. In my experience, this was usual practice on the unit.

71. I think that Dr Colvin wrote to patients, and their GPs, after clinic visits to explain the results of non-urgent blood tests.

Liver function tests

72. Liver function tests were carried out routinely. If the results were abnormal, patients attending clinic would have a discussion with Dr Colvin about the test results and what they indicated.

73. Many patients had blood results indicative of prior infection with non-A non-B hepatitis. Prior to a test becoming available for hepatitis C, in addition to the patient's history and clinical examination this was the main way of establishing if a patient was infected. Dr Colvin would explain the significance of the test results, and the extent of the liver problems that the results indicated. Patients were also given advice about reducing alcohol intake. After testing for hepatitis C became possible, liver function tests continued to be monitored and the results and possible health implications were explained.

74. All patients with liver disease were jointly cared for by Dr Colvin and a consultant gastroenterologist, Dr Swain.

Tests for HBV and HIV

75. All new patients were vaccinated against HBV. I remember administering vaccines and taking blood for monitoring patients' antibody levels. We had a few patients who had previously had HBV infection. As far as I can recall there were no new cases of HBV after 1985.

76. Most of our patients attended clinics regularly. To the best of my memory, the patients who were receiving blood products were tested for HBV (antibody or antigen) and HIV at every clinic. The risk, by this time, of any new infections was thought to be very low due to HBV vaccination and the heat treatment of

blood products. I think there were no new cases of HBV or HIV in our patients treated after about 1985.

77. New patients who received treatment with blood products would be given an explanation of the purpose of tests when they were seen in clinic and prior to tests being carried out. Patients were advised to approach the Haemophilia Society in relation to travel insurance. The Haemophilia Society had an arrangement with an insurance company that enabled patients with haemophilia including those who had been tested for viruses to obtain travel insurance. There was a problem generally with individuals who had been tested for HIV obtaining insurance.

Testing for HCV

78. An information letter was sent to patients about Hepatitis C but I cannot recall when the letter was sent.

79. I have no memory concerning the initial testing of all our patients. It may have occurred when I was on maternity leave, or otherwise absent, or I may have forgotten. I recall that almost all of our patients who had had treatment with factor concentrates before 1985 turned out to be positive.

Obtaining consent

80. There was no specific training on obtaining consent for blood testing that I can recall. I considered ensuring that patients gave informed consent to be a requirement of my role and to be best practice.

New patients

81. I do remember an occasional patient arriving with a bleed, who had not been to the centre for many years or had been registered at another centre but had received factor-concentrates prior to 1985.

82. Dr Colvin or, in his absence, his senior registrar, saw those patients with me for an assessment, and an explanation about the risks of viruses in relation to their previous treatment. We would obtain informed consent before testing these patients for HIV, HCV and HBV. All HBV seronegative patients would be offered vaccination.

83. I have been asked which senior registrar saw these patients. I do not remember. There were several senior registrars over the period that I worked at the centre. I have given the names of those that I remember in paragraph 27 above.

Testing of partners and family members

84. I believe that known partners were tested for HIV and HBV before my arrival in 1989.

85. I think that we tested the partners of patients who were found to be infected with hepatitis C. I do not recall testing children or other relatives. I do not have a clear memory of this period. Testing may have taken place in the community and/or at a time when I was absent.

86. Partners and family members who attended clinics or meetings with Dr Colvin were fully involved in discussions about risks and prevention of infection, if the patient consented to this.

87. In cases where patients requested that we did not share information with partners, we explained the importance of sharing this information and offered to speak to the patient and his partner together. I think, in all cases, the patient subsequently consented to the sharing of information with partners.

Test results

88. As soon as the results were available, we would telephone the patient. I think that we would give negative results over the phone; however, if the result was positive, we would ask them to come in. Dr Colvin would explain the results, the implications, the treatment and follow-up required. One of the nurses was usually present at these consultations. These consultations were documented in the patient's notes.

89. I can recall being present when Dr Colvin explained a positive HCV result to a patient. I was in clinic when patients who had previously been told were reminded, by Dr Colvin, of their positive HCV result, the implications and possible treatment options.

90. I was often asked to clarify the information that the patient had already been given; I would answer all the patient's questions. I remember one patient who had been informed about a positive HCV result telling me at his next clinic that he had forgotten about being told.

Care of infected patients

91. Treatment of patients with HIV, HCV or HBV was managed by Dr Colvin and the haemophilia team in conjunction with the hospital's HIV team and a gastroenterologist who supported the patients with hepatitis

92. To the best of my memory, all our patients with a low CD4 count or a diagnosis of AIDS were offered treatments as they became available. Treatments included zidovudine and other anti-retroviral drugs from the late 1980s, and HAART in the mid-1990's. Patients with HBV and/or HCV were offered treatment, including interferon and ribavirin.

93. As new treatments for HIV and HCV became available patients were informed and offered the appropriate treatment. Advice about maintaining good health, including reducing alcohol intake was given to patients at their clinic visits.

94. Follow-up and on-going monitoring of patients with blood-borne virus infection took place at regular clinic visits with Dr Colvin, a member of the nursing team, and a gastroenterologist or HIV specialist or both.

95. Dr Colvin offered these patients a second opinion, where he or the patient felt that this would be helpful. Patients were referred for a second opinion to the Haemophilia Centre at the Royal Free Hospital. I recall one patient being referred for assessment to the liver transplant unit at the Royal Free Hospital.

Managing the risk of cross-infection

96. Patients were advised about the risks of sexual transmission to partners and about practising safe sex. Condoms were freely available in the centre. A patient information leaflet about safer sex, produced by the Haemophilia Society, was available to patients. A trained counsellor who worked in the Ambrose King Centre also provided advice and information regarding safer sex to our patients. I cannot recall the name of this member of staff.

97. The advice about safe social contact was based on what was known at the time; for example, we advised against sharing toothbrushes.

98. Patients receiving home treatment, and their families, were advised about safe venepuncture practice and the safe disposal of clinical waste and needles; sharps bins were provided by the centre and collected from patients' homes. Family members who administered treatment to haemophilia patients were advised about hand washing, wearing gloves, safe disposal of sharps, and to have hepatitis B vaccination. These patients received regular follow-up and support from the haemophilia community sister.

99. In the centre, we operated a 'mini' universal precaution policy. Those who had HIV, HBV and/or HCV were treated the same as other patients. We wore gloves for any procedures that involved contact with a patient's blood or bodily fluids, whether the patient was known to be infected or not. The hospital's infection control policy regarding disposal of contaminated clinical waste and sharps was followed.

100. Since the precautions were universal, it was not necessary to inform all members of the clinical staff of a patient's viral status. To the best of my memory, patients' viral status was documented in their notes. When infected patients were referred for surgery, dental treatment or other invasive procedures, the clinicians were informed of their infections.

My role

101. My role included providing advice, support, and advocacy for patients with HIV, HBV and/or HCV and liaising with the multidisciplinary team to ensure they received a high standard of care and support. I liaised closely with the community haemophilia nurse and occasionally we made joint visits to support patients and their families in their own homes.

102. I saw in-patients every day that I was on duty, and would often accompany patients to other departments within the hospital if they required specialist investigations or care. I would attend patients in other wards and departments to give them their blood-clotting treatments, and to advise the staff on those wards about care of patients with haemophilia, and otherwise to provide support.

103. I was frequently asked to share my knowledge and experience of supporting patients with haemophilia and HIV HBV and/or HCV with other staff in the hospital.

The stigma

104. Patients and their families affected with HIV, HBV and/or HCV did talk about the concern of being stigmatised in the community and in schools and workplaces. Haemophilia became associated with HIV and viruses in the 1980's. As a result, patients with haemophilia who were not affected with HIV HBV and/or HCV also spoke to us about feeling stigmatised.

105. The community nurse's regular visits to schools mitigated some of the problems that children with haemophilia and their families experienced. Our patient support groups, which I attended, and the other community support groups that some patients joined, gave patients and their families the opportunity to share experience and give each other mutual support.

106. Many of our patients did not share their haemophilia, HIV HBV and/or HCV diagnosis with employers. However, I think that our community nurse visited places of work to support and educate employers, if requested by the patients to do so.

Counselling and psychological support

107. The wider multidisciplinary team within the hospital, who supported our patients with HIV and /or HCV, included specialist HIV doctors and nurses, a counsellor and social workers.

108. Patients were used to receiving support from Dr Colvin and other members of our team. They would speak to us about how they were coping. We would provide support. I am not sure if anyone in the team had any formal counselling training, except for the social worker. However, we developed counselling skills through experience.

109. We worked closely with, and referred patients to, the Haemophilia Society, the Hepatitis C Trust, the Terrence Higgins Trust, and the Mild May Hospice, all of which offered further support to our patients.

Social work support

110. We had a specialist social worker who advised and supported patients living with HIV, HBV and/or HCV. He saw our patients regularly, often with me, and may have also made home visits with our community nurse.

111. An evening support group for patients and their families was started by the HIV social worker and me. I recall that the first meeting was held in the hospital, however, subsequently carried on in the community. Dr Colvin and I often attended these community patient support meetings.

Research

112. I was involved in research studies, as set out below:

Concorde

113. This was a Medical Research Council (MRC) double-blind study of the use of zidovudine in symptom-free patients with HIV. One patient at our centre was included in the study. Dr Colvin was the named researcher at our centre. I was involved to the extent that I took blood samples from the patient according to the study protocol. I was the point of contact if the patient needed advice or support.

Alpha interferon for hepatitis C infection in haemophiliac patients

114. The research consisted of a controlled trial in 20 patients with haemophilia in which intravenous recombinant interferon alpha-2a, 3 mega units thrice weekly, was used to treat chronic hepatitis C infection. We conducted this trial jointly with the Royal Free Hospital. Less than half of the patients in the study

were from our centre. Clinicians involved in the study were P. Telfer, H. Devereux, B. Colvin, S. Hayden, G. Dusheiko, and C. Lee. My role was to take blood samples, to give the interferon, and to be the first point of contact if patients had questions or concerns about the treatment.

Recombinant factor VIII study for patients who had not previously received treatment

115. To the best of my memory, we had a very small number of patients enrolled on this study, possibly one. Clinicians involved in the study were Dr Colvin, the community haemophilia nurse and me. My role was to administer treatment, take the blood samples, and to support the child and his family.

Recombinant factor IX study for patients who had not previously received treatment

116. Again, to the best of my memory, we had a very small number of patients enrolled on this study, possibly one. Clinicians involved in the study were Dr Colvin, the community haemophilia nurse and me. My role was to administer treatment, take the blood samples, and to support the child and his family.

Information given to patients

117. Patients were always made aware when they were involved in research. Patients met with Dr Colvin; he explained the nature and purpose of the research and gained informed consent. We always provided information leaflets about the study. Consent was documented according to the protocol of the relevant study.

PUPS

118. I have been asked what the term 'PUPS' means to me. I understood PUPS to be an acronym mainly used in the literature to describe patients who had not previously received treatment with blood, blood products or concentrates. I

have no recollection of it ever being used in respect of an individual patient, my recollection is that it was used by clinicians discussing groups of patients in research studies.

Variant CJD (vCJD)

119. To the best of my memory, around the mid to late 1990s, information about vCJD was published in literature and was discussed at meetings of haemophilia clinicians.

120. We had a record of the batch numbers of all blood products given to patients. I think that we called people in who had received treatment from batches that were potentially infected. I cannot recall how the Centre was made aware that there were potentially infected batches. I think that patients were also informed by letter of the possibility of exposure to vCJD. I am unsure if the letter was sent before or after patients had a consultation with Dr Colvin about vCJD.

121. I remember being present at a meeting between Dr Colvin and the parent of a patient who had received blood concentrates from one of the identified batches. The concerns about the risks of vCJD were explained to the parent and reassurance and ongoing support offered. I cannot recall specifically what information was given. As always Dr Colvin would have recorded the consultation regarding vCJD in the patient's notes.

122. I cannot remember any more about vCJD. To my knowledge none of our patients contracted vCJD.

Effect on clinical staff

Risk of infection

123. The hospital had infection control procedures in place when I arrived. These were the 'mini-universal' precautions described above. There was little

change to these precautions during my employment. I can recall that a protocol was introduced for administration of zidovudine to clinical staff who had received a needle-stick injury that put them at risk of HIV infection.

Reporting concerns

124. We had an incident reporting system. We would complete an incident form if there was an error, or concern about staff or patient safety.

125. These incidents would be reported to Dr Colvin. He would ensure that the patient was informed, and would take action as necessary.

126. I remember once being sprayed with blood when putting blood into a blood culture bottle. I talked about my concerns with Dr Colvin, and was re-assured there was no risk in the circumstances. I also remember a junior doctor reported receiving a needle-stick injury and, although I was not present, the incident was addressed by Dr Colvin according to the appropriate protocol. I cannot recall what the Centre's protocol was at the time of the incident. I was not directly involved. My memory is more about being confident and impressed at the time with the thorough and professional approach adopted by Dr Colvin in dealing with the incident.

127. I once raised concerns about the treatment given to a patient with Von Willebrand's disease by a junior doctor; I believed that the prescribed dose of DDAVP was incorrect. I reported my concerns to Dr Colvin who dealt with it immediately. I completed an incident form on the ward and the incident was documented in the patient's notes and the patient/guardian was informed.

128. Those are the concerns that come to mind. I may well have had others over the years, but do not recall them.

Impact on me

129. When I took up my post the patients had already contracted the infections from the treatment they had received prior to 1985.

130. From a personal and professional point of view I felt well supported within the team, and particularly by Dr Colvin, whose office door was always open to any member of staff with a concern. Dr Colvin's continued support for all his staff and the support of nursing and medical colleagues and other members of the multidisciplinary team was very important.

131. Supporting patients that I knew so well, who were becoming severely unwell and dying due to HIV and/or HCV infection was personally very hard to deal with. The effect this had on individuals and their families was devastating and difficult to witness. It was challenging to ensure this experience in professional life didn't impact negatively on personal life outside the hospital. From a professional perspective it emphasised the importance of being part of a dedicated and mutually supportive team who understood the challenges. I also appreciated that I worked in an environment where I believe the highest standard of patient care was being delivered under Dr Colvin's leadership.

Other Issues

Financial support

132. Patients at our centre were referred to the Macfarlane Trust and were supported by them financially. I recall liaising with the Macfarlane Trust to gain information about the type of assistance they may be able to provide for patients. I visited their London office to meet the staff, to learn about their work, and to collect patient information literature for our patients.

133. On occasion patients told me that they were receiving financial support from the Macfarlane Trust. I cannot recall any patients saying that they were having

difficulty obtaining funding. I cannot remember whether I personally supported applications or not.

134. Patients usually accessed this support independently from what I can remember. We would remind patients in clinic that support from the Macfarlane Trust was available and check that they knew how to access this support if they wished. I have no recollection of having to get involved in supporting individuals in their applications, however, Dr Colvin and other staff may have.

Records

135. Each patient's treatment was documented on a treatment sheet and in their patient notes.

136. Dr Colvin kept what was then called a 'brown envelope' system. This was a duplicate set of clinic letters and important notes about the treatment and follow-up for all registered patients, so that this information could easily be accessed by doctors who saw the patients out of hours.

137. I cannot remember what the record retention policies of the Hospital were during the time I worked there.

Conversations with Dr Colvin

138. I have been asked by the Inquiry what prompted a conversation that I had with Dr. Colvin in March 2020, about testing for HCV, and to include his response. Dr Colvin sent me a WhatsApp message. This was not unusual as we have kept in touch socially since I left the hospital eighteen years ago. He wrote in the message that he had been asked questions by the Inquiry and that he would like to tap my memory about general matters but he would not be able to discuss specific complaints. In the message, he also asked what year I came to the Hospital.

139. We later spoke on the telephone. I told him the year that I started at the Hospital. I cannot now remember exactly how the conversation went after that, but I think Dr Colvin asked me what I remembered about the Centre's communication with patients regarding HCV testing.

140. I said that I could not recall anything about the testing of our existing patients for HCV, either because I had forgotten or was not present at the time. I mentioned that I thought an information letter was sent to patients but I could not remember when the letter was sent. I think I said I was not sure if I had contributed to drafting the letter or if I had just read the letter in patients' files.

141. I told Dr Colvin that I could only remember testing previously treated patients who were new to the hospital or who had not attended for many years. I explained that I remembered that he consulted with these patients, with me present, and that I took blood samples after obtaining informed consent. Dr Colvin said this was helpful information but that he could not remember this. I cannot recall discussing anything else in our conversation.

Documents

142. I can confirm that I do not have any documents that may be relevant to the Inquiry's Terms of Reference.

Statement of Truth

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

Signed: GRO-C

Dated: 01/11/21