Witness Name: **Tracey Dunkley**

Statement No: **WITN5716001**

Exhibits: **Nil**

Dated: **27 February 2023**

# INFECTED BLOOD INQUIRY

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## WRITTEN STATEMENT OF TRACEY DUNKLEY

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 01 September 2021;

I, Tracey Dunkley will say as follows:

**Section 1: Introduction**

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

**Name**: Tracey Dunkley

**Date of Birth**: GRO-C 1967

**Current job**: Registered Care Manager

**Qualifications**: Register General Nurse; Independent Medical Prescriber; Advanced Nurse Practitioner.

**Please set out your employment history as a nurse, including the positions you have held, the dates that you held these positions, the haemophilia centres and other organisations in which you held these positions and your role and responsibilities in these positions.**

**1989 October - 1991 October**

1. I worked as a Staff Nurse in the Neurosurgical Ward at the Queen Elizabeth Hospital. I was a staff nurse on a 19 - bed Neurosurgical ward. As a staff nurse, I gave out medication, and took patients to the theatre, supported patients back from theatre, was a mentor to students, and dealt with families.

**October 1991- October 2000**

2. I worked in the Intensive Care Unit, part time working nights at the weekend. I worked in the Cardiac Intensive Care Unit and General Intensive Care Unit which included liver surgery and transplants.

**May 1995 – 2000**

3. I was a Junior Sister. This was for 2.5 days in the Haemophilia Unit. I gave Factor VIII/IX products, took bloods, helped with assessments, supported during doctor's clinics, help with haematology clinic, supported families, completed the paperwork, completed the Oxford stats. The stats were an annual checklist of all products used including desmopressin, for every patient, also including severity of bleeding disorder. The paperwork took many days.

**2000 - October 2016**

4. I worked as the Clinical Nurse Specialist. I was responsible for managing the unit, organising blood products, monitoring finances and spending on blood products, counselling services, supporting some community work. I worked with Mark Simmons closely, by supporting patients. My role changed as treatments continued to improve and we were then focusing on those with HIV and those who were also co-infected with HIV and HCV.

**2016 – present**

5. Registered Care Manager of a nursing home for adults with learning disabilities and complex health needs. I knew the care home very well, as I visited and treated one of the haemophilia patients who lived there, while I was still in the NHS.

**Please set out your membership, past or present, of any committees, groups, associations, societies or working parties relevant to the Inquiry's Terms of Reference (which can be found on the Inquiry's website at www.infectedbloodinquiry.org.uk), including the dates of your membership and the nature of your involvement.**

**2002 – 2004**

6. I was a member of Haemophilia Nurse Associations. I joined in 1995 when I started working in this field. Although my name appears on the committee for the HNA in 2002, I believe I was on maternity leave then and had no part in the organisation of any events. I did attend several HNA's but only one as part of the committee.

7. I was also seconded to the Committee for organising (Baxter's global conference), where we are developing haemophilia thinking and strategy with nurses from all over the world. The Conference that took place in 2004.

**Please confirm whether you have 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. If you have, please provide details of your involvement and copies of any statements that you made.**

8. No. I have never been directly involved but I have helped some patients get records for civil litigation. I would receive an approach from the patient and the records I refer to, were

the medical records held on the unit for that patient. The patient had to fill in an application to access their notes and this had to be agreed by every medical Consultant they were under before a copy of their medical records was sent to them.

**Section 2: The haemophilia centre at Queen Elizabeth Hospital Birmingham ("the Centre")**

**Please provide details of your role within the Centre, including the dates when you worked there, your responsibilities and, if you can remember, names of significant or senior staff members who were working there at the time.**

9. I worked in the Haemophilia Unit from 1995 until I left in in 2016, initially as a Junior Sister, working part time 2.5 days per week under Dr Jonathan Wilde (Consultant). He was there throughout my time. Jane Linin (Clinical Nurse Specialist) was also there when I started. I became full time in 2000 taking on the role of Clinical Nurse Specialist/Unit Manager. My roles and responsibilities during those times I have outlined above.

10. I worked with Samantha Day and Jill Wilson; they both were Community Liaison Nurses.

11. Angela Beckett was also a junior sister on the unit when I was the manager.

12. I worked closely with Mark Simmons who was a social worker and began working on the unit in 1998.

13. Later on, in my career, I worked with Will Lester (Consultant) and also Gill Lowe (Consultant).

14. Then there was Pam Green, who was also a Junior Sister who joined later.

**Please explain the hierarchy and dynamics at the Centre, identifying in particular who was responsible for (a) decisions as to the selection and purchase of blood products, (b) decisions as to use of blood products (including factor VIII and IX concentrates) for patients' treatment and (c) decisions as to what information to provide to patients about treatment, testing and/or diagnosis.**

15. Dr Wilde was overall the main person responsible for the decision making regarding the use of blood products. During this time, it was the Medical Consultant, i.e, Dr Wilde and the Companies, through their reps, who would liaise with each other. The companies were mainly Baxter, BPL, CSL (The rep was called Helen Carroll) and Alpha. Then the UKHCDO started to take responsibility and decide on the usage of blood products. It became about the need to be cost effective and the ability to bulk buy. Bigger centres bought larger volumes of products so were able to get the products at a cheaper price as they were able to bulk buy. Smaller centres with fewer patients bought a smaller number of units of product so had to pay a higher price. The UKHCDO asked companies to put in a tender via sealed bids. This enable all centres to be paying the same price for all products. The UKHCDO would then discuss which centres would have which products to ensure the agreed units were purchased and therefore, the prices were the best available.

16. Dr Wilde looked after the patient's treatment and made decisions about products that would be used. We didn't tend to swap people's treatments around because of concerns about the development of inhibitors. Later, the patients had more of a say to which products they were treated with.

17. The information which was given to patients varied depending on what was known at the time. Both Dr Wilde and the Liver Consultants worked closely with the patients. I feel Dr Wilde was very open on the clinical side of things and how things were progressing regarding HIV and HCV and the risks that it posed.

18. When children moved to the adult centre at the Queen Elizabeth, they would be surprised by a lot of things that were not known to them up until that point. For example, tests they had had. It was not unusual for patients to be transferred from Birmingham Children hospital at the age of 20 years old or older. This tended to occur if they were HIV or HCV positive. They should really have transferred at around 16 or 18 years old. It made it difficult when a young person needed admitting to hospital as being in a child's bed in a children's hospital had its problems. With the focus on how we support children to transition to the adult centre, 16-18 years old became the more common age for them to transition to the adult centre.

**Section 3: Knowledge of risk**

**What was the Centre's approach and the approach of senior clinicians at the Centre, including Dr Jonathan Wilde, to the use of blood products (in particular factor VIII and IX concentrates)? How did this change or develop over time?**

19. Our centre tried to use mainly BPL and British products, as the patients saw American blood products as the main risk. We had faith in the blood products especially with Dr Wilde.

20. We had very few products that were Alpha when I started.

21. When I started, Factor VIII (8Y) cost approximately 18 pence per unit; whilst Replenate cost approximately 24 pence per unit. We used Replenate for HIV positive patients because it was a high purity product which had less impact on the patients CD4 count. We eventually used Recombinant products which were 40 pence per unit plus VAT. Patients then started to ask for Recombinant products, and they would be allowed to move on to recombinant products sometimes, but it would depend on supplies and pricing and clinical need.

22. In 2004, the protocol was that PUPs were given Recombinant as priority. Then those considered for Recombinant would be started in age groups, with the older patients being the last to receive Recombinant. I think this took 1 - 2 years to fully introduce.

23. Some of our patients went on a treatment strike. Some of them suffered and tolerated horrible bleeds. They refused to use blood products, because they had infections already, they didn't think they should have to wait for the recombinant products. The older patients who were 40 years old plus, were the ones who had the poorest, worst affected joints, and they had some horrendous bleeds, but they were not successful in their strike, and they had to wait for the protocol to be followed. It was heart-breaking at times to see people you grew to know personally suffer this way but there was a limit to what could be done.

24. With 'Recombinant for All' the 'Haem-track' digital system was set up in 2008 so, for example, a patient who was dispensed 50 bottles, 50,000 units for home treatment, would be added to the tracker. Product details and batch and unit numbers were recorded. Their usage would be monitored and the system would monitor the effectiveness, and in what scenarios the patient needed to use the blood product. The system was able to show why the patient was using the products, and why they needed more and if this was appropriate usage. The patient would enter in these details themselves from drop down boxes. This was to help to monitor costs by looking at usage. Any products used in the Haemophilia unit would also be entered but by the nurses.

25. Dr Wilde tried to keep the same product with the same patient. He tried his best despite the financial pressures.

26. In 1995, our blood product budget for the unit was £3 million but we were always over budget for buying blood products. By 2016, there was a budget of £10 million allocated for blood purchasing blood products.

27. In around 1999, external auditors were brought into the Haemophilia Unit to look at our finances, as we were always deemed to be 'over' budget. The auditors concluded that we had been underfunded and were not over budget. At this time the budget was then increased to around £5 million.

**What was the Centre's approach and the approach of senior clinicians at the Centre, including Dr Jonathan Wilde, to home treatment and to prophylactic treatment for patients with bleeding disorders? How did this change or develop over time?**

28. When I started on the unit, Dr Wilde wasn't originally an advocate of prophylaxis although he later became convinced of its merits. Clinical trials showed prophylaxis was more effective in the long term as patients had fewer bleeds and prophylaxis helped to protect joints. It was more expensive than 'on demand' treatment as it was used every day or every other day, as opposed to when required, but at the same time prophylaxis clearly reduced in-patient episodes and outpatient attendances. During this early period the doctors were still the decision makers about home treatment. The idea was not widely supported to give prophylaxis treatment at home possibly due to the potential cost. However, I remember that St Thomas's Hospital had commenced prophylaxis treatment with their severe haemophilia patients. They were reporting successful use of prophylaxis but this would mean a massive cost to centres. It made prophylaxis difficult to oppose particularly when they results spoke for themselves.

29. When I left in 2016 the majority of the patients were on prophylaxis treatment, except those who had inhibitors whereby, only a few were using prophylaxis.

**What was the Centre's approach and the approach of senior clinicians at the Centre, including Dr Jonathan Wilde, to the use of factor concentrates for children with bleeding disorders? How did this change or develop over time?**

30. We were an adult centre so children wouldn't come to us until they reached at least 16 years of age. Sometimes they could be in their 20's when they transferred to us, due to being infected with HIV and/or HCV, it was decided by the consultants at the Children's' that they should stay at the Children's centre for longer. There was no proper management of the transfer process, and it could depend on their individual treatment plan, until a focus was put onto 'transition' and support to enable young adults to move from children's care into adult care sooner with support. Initially the children with severe haemophilia who transferred, would be taken off prophylaxis treatment, as it was thought they didn't need it. This then changed as more trial information showed prophylaxis was essential for ensuring protecting joints and preventing joint damage.

31. At the time, we were not involved with Children's haemophilia care directly, in Birmingham. Sometimes they transferred to us at 16 years old, but it was mainly after the age of 18. There were some issues that were discussed, whereby if young adults needed social work support, they could be supported by a social worker at the Children's Hospital at 16 and by an adult social worker at the adult centre 18 but there was no one to support 17-year-olds. 17-year-olds fell between the 2 cut off points. Sometimes the 17-year-olds had to be advised

to contact the Citizens Advice Bureau, for any issues that required a social worker. We could take their blood and sort out their blood products, etc but couldn't help with any social work side. We could liaise with the social workers but it didn't go beyond that.

32. We had one young patient, whose parents didn't know he had HIV. The children's hospital told him on his own, then transferred him to our adult's centre. He never told anyone. At 16 years-old he was given this devastating news alone. This had a massive impact on his adult life.

**Do you recall any policies or standard operating procedures (written or otherwise) relating to the use of blood products being in place? If so, please describe what they were and whether they changed or developed over time.**

33. We always had SOPs in place, for example, 'The Haemophilia Booklet' which was in use when I started but I can't say for how long. We would review this annually. These were printed booklets. Basically, the booklet would detail what haemophilia is, what constitutes an emergency, how to calculate a minor bleed and a major bleed. In addition, as blood products changed the booklet would be updated. Dr Wilde would write it. I would read through it and check this with my colleagues. Those who were infected with HIV etc, were to be treated just the same as other patients. Anyone working on the Unit was required to be familiar with the booklet and procedure. It was the same with all SOPs. With the booklet, as mentioned Dr Wilde did the review although I did assist at times and often a team effort was involved.

**What was your general understanding as to the risks of infection associated with the use of blood and blood products? What was the source of your understanding? Were you provided with any information or training, whether at the Centre or elsewhere, about the risks of infection and if so, when? How did your understanding develop over time? How did your knowledge affect your nursing practice?**

34. I didn't have a great understanding of the products, certainly not initially. I did a course on how to look after people with HIV which was an ENB course specific to anyone with HIV. I would go to the clinical nurse specialist or the other haemophilia nurses if I wanted advice and would learn from the consultants mostly by watching and listening.

35. There were no external courses, nothing until the haemophilia course came in.

36. There was an external Haemophilia course, brought in for dealing with haemophilia, and eventually an Advanced Haemophilia course but I had already done my Masters by then so I didn't do the course. Much of what you learn was self-taught.

37. There was no training for working with haemophiliacs with HIV, it was simply learning on the job. The HIV doctors in the local area – I recall Dr. Jonathon Ross and Dr. Manarvi, would come in and sometimes nurses would be allowed to attend their talks and learn from them that way.

38. There were courses and training being provided before I left, and I am sure things will improve further.

39. There was a lot of stigma attached to HIV. Some patients did not want the related stigma to impact on them or the haemophilia community as HIV was commonly seen as related to homosexuals and drug use by the public. This was not helped by the adverts in the 1980s which included images such as tombstones.

40. It was so secretive at this time because of the fear of this stigma. In 2013 - 2014, we joined up with the Genitourinary Medicine Unit (GUM). This unit was run by Dr Manarvi. Patients reported that when they attended, they were asked much more personal questions such as "tell us about your sex life" by the health advisor, then told to go to see someone else such as the dietician. Patients reported saying "You had to do this and this…" The patients didn't like this approach. When we initially agreed to the merger, we thought we would hold clinics jointly, the HIV doctor and haemophilia doctor both working together. We thought this would be a combined effort and therefore, better for the patients. But they (GU) took over the HIV care completely.

**What was your understanding as to the risks of the transmission of hepatitis (including Hepatitis B and Non-A, Non-B Hepatitis/Hepatitis C) from blood and blood products? What was the source of your understanding? When did you first become aware that hepatitis could be transmitted by blood or blood products? Were you provided with any information or training, whether at the Centre or elsewhere, about the risks of the transmission of hepatitis and if so when? How did your understanding develop over time? How did your knowledge affect your nursing practice?**

41. With the haemophilia units, the main patients we saw on a regular basis were those who were HIV positive or severe haemophiliacs. There were some who had HCV and some who were co-infected. I was aware of the risk of blood-to-blood transmission and the need to use PPE which was always the case, but I can't say specifically when I became aware. It may well have been part of my initial nurses training. As the virus became more understood precautions adapted. There were very few patients on home treatment when I started. We used to have regular clinics and would take blood and always adhered universal precautions. In the back of your mind, you are aware there is always a risk but it is your job.

**What was your understanding as to the risks of the transmission of HIV from blood and blood products? What was the source of your understanding? When did you first become aware that HIV could be transmitted by blood or blood products? Were you provided with any information or training, whether at the Centre or elsewhere, about the risks of the transmission of HIV and if so, when? How did your understanding develop over time? How did your knowledge affect your nursing practice?**

42. Coming into the Unit, people who were HIV positive and HCV positive were mainly infected from American blood products. That was my initial understanding, and this came from my induction and experience on the haemophilia unit, from talking with patients and sitting in the clinics and from having attended the Haemophilia Nurse Conferences – I believe my first was in October 1995 in Manchester. I found this out when I started full time in the Unit. As a nurse I knew about HIV and HBV, but it was only when I joined the unit in 1995 that I got to understand about HCV. It used to be known as Non-A, Non-B hepatitis before it was named HCV. It was common knowledge that it was known there was something in the product many years before, as many people developed jaundice and subsequently went on to develop HCV.

43. Scientists knew about CJD in the 1970s from my understanding. There is nothing factual or documented, I simply remember a staff member from the laboratory told me about this. I can't say this was vCJD but they certainly knew about CJD.

44. In 1998, we began to work a lot with the Liver Unit. Dr Shields a Hepatology SpR was very interested in HCV. At this time, we started looking at Interferon and Ribavirin as part of a clinical trial. We were allowed to nominate patients on compassionate grounds to enter the trials for Interferon/ribavirin, as the criteria to qualify for the trial was very strict.

45. I personally became more involved with the psychological support. Some people with HCV, required end of life care, and had liver failure and it was a lot to deal with. Some of those who were able to have a liver transplant were also, co-infected (HIV/ HCV) and were often given what was considered a poor-quality liver. For some who had a liver transplant the new liver would start to fail. If they were only infected HCV, I believe the liver available would be a better-quality liver. If you were co-infected and had a liver transplant you would be expected to have a lower life expectancy.

46. When I first started on the unit, some HIV patients would come in as inpatients, and labels would be out on the door to their room that read 'Hazard' or "Warning" This generally happened when the infection control team were involved, and the patients were on wards or in a side room. It was to notify other staff of the infection but of course alerted others who were not caring for that person including visitors to the ward. I challenged this on occasion when I became aware as it meant the patients were seen as different but often it was a lack of understanding, education or miscommunication that led to the labelling in the first place. In our unit everyone was treated in the same manner.

47. With HIV, HCV and any other risks you became aware quite quickly. With HIV it was from basic training when I entered the unit as a junior sister. HCV, I learned more about when working with patients on the liver wards and in the Outpatient Liver Unit. There were no formal training sessions, but we passed on best practice. There was no advice for double gloving or gowning or anything. We always wore gloves, and we took the same precautions for every patient. These viruses didn't affect our work, they were just universal precautions that everyone should have been using regardless of whether the person had HIV or HCV.

48. A lot you learned as you went along, you often learnt from the patients themselves who would remind you of their status.

**What was your understanding of the relative risks of infection from (a) the use of commercially supplied blood products and (b) the use of NHS blood and blood products? How did your understanding change or develop over time?**

49. I believed that British products were safer. From 1995 onwards, British products were seen as safer and American products were infected from my understanding. This came through on the job training and literature and information from colleagues.

50. There was some litigation where patients tried to sue the Americans. I think some were successful but they signed an NDA. I can recall GRO-A and possibly GRO-A GRO-A, as two who became involved although they were not as successful as the American litigants. I don't really know any more about it though.

51. During lookback studies I would see 'BPL' on their factor usage records and then you would see, one day that they received an 'Alpha' product. You would think, oh god it could have been that day that they were infected, and vice versa. It was hard to read through the medical records and not be affected by this. It was emotional.

52. As a part of the look-back exercise, I realised it was also British products that were infected with some viruses.

53. In the haemophilia unit, there would be a 'do not destroy' label on the haemophilia notes. This was at the 'Queen Elizabeth Hospital', but in 2011 they started to go digital. We kept our notes in the haemophilia unit, they theoretically should still be there now. I'm not sure when it started as it was the system when I arrived in 1995. I don't know if it was a policy or just a local decision as it was it was thought that families may need access to the notes in the

future – legal actions had started to be brought around that time. There was also the medical benefit of access if there was a query involving a family history. Even after the digital conversion started, we retained some of the more important notes as we had no control over what was scanned in and what was not.

**Was any training or advice provided (and if so, what training or advice) to clinical staff at the Centre in relation to advising patients of the risks of infection associated with the use of blood and blood products? Who provided this training or advice?**

54. I don't recall any advice to be given on the risk of the products themselves, but this would have been the job of the doctor when originally prescribing the particular product. We would advise on safer sex practices. We would educate patients on undetectable viral loads, and how to conceive naturally. At this time, the risk of contracting Hepatitis C was deemed to be less than 1% when having a sexual relationship with the same person, so the literature said that there was no need to practice safer sex but, if you had multiple partners, you were encouraged and advised to practice safer sex. This did seem strange to me at the time but as a junior nurse I accepted the advice of the Liver doctors who had expertise in this area.

55. I learnt as I went along with the psychological support. But there was no training on this. We had people such as Dr Ann Bond who helped us with psychological support. Mark Simmons' background was HIV. He worked in this field from when HIV was first known about and discovered. I would speak with him. We would talk about Dr Wilde's patients and how to best help them with Dr Bond. Mark also helped with counselling as he had a vast experience of this. Any sessions by Mark or Dr Bond would be recorded in their medical notes. These were brief notes which did not go into detail about the session but recorded that a session had taken place. However, there was no protocol for support.

56. We also had liaison psychiatry support from Dr White. A psychiatrist (SpR) would come to the unit every 6 months or so and see patients there. Once Dr White had retired this service seemed to disappear.

**Were any steps taken at or by the Centre to mitigate or reduce the risk of infection from the use of blood or blood products? If so, please detail what steps were taken and when.**

57. We tried to treat every patient the same as mentioned. The product they were using would remain the same one to try to minimise any risks that may come from changing products. By the time I started on the unit products were already being heat treated. Then as technology developed, products would go through a manufacturing process of solvent detergent treatment, to enhance safety. As knowledge grew, rules around blood transfusions were developed further and the level of haemoglobin at which a blood transfusion would be offered were much lower or the person had to have severe symptoms.

58. Once vCJD was discovered, blood transfusions were white cell depleted as it was known that it was the white cells which were part of the transmission route.

**Section 4: Testing, treatment and care of patients**

**What information was provided to patients at the Centre about the risks of infection (generally and/or specifically in relation to hepatitis and/or HIV) associated with the use of blood and blood products, and by whom?**

59. By the time I started on the unit, all the patients then knew about HIV and HCV. There was no written literature available that I recall, but I think they could have a sit down with the

doctor. Initially with vCJD, none of us really understood the route of transmission until it was discovered as shown above. There was little information until then. Patients and staff would always ask things. The companies, including Baxter, Grifols, Bayer, etc would give information about how their products were manufactured and the risk of vCJD in the products.

60. The companies did financially support the unit to enable us to provide training days for nurses within the West Midlands region. The nurses set up the days and decided on the agenda and who should speak. Doctors were also invited to speak and share their knowledge about bleeding disorders. They also supported National and International conferences to enable the sharing of best practice. These would have input from the companies directly.

61. The companies also funded days for the unit such as the 'Women's Day' for those infected or affected by (haemophiliacs infected with) HIV, Mothers (and father's) day for those with HIV positive haemophiliac sons. The companies were not allowed to attend the days or have any say on the agenda.

**What information was provided to patients at the Centre about alternatives to treatment with factor concentrates, and by whom?**

62. Not a lot at all. We had Dr Ann Bond, a specialist in psychological support come in and she would provide counselling. It wasn't an alternative treatment but to assist well-being. Bobbie Reid was a CNS for psychological support who also supported our patients. We did have a SpR in Liaison Psychiatry once every 6 months.

63. We didn't have a homoeopathy at the unit but some time later we were able to access one in the Cancer centre.

64. We had a physiotherapist; her name was Jeanette Batchelor This post was developed to help maintain haemophilia patient's joints. Jeanette coming to the unit was much later. When I started, we would just refer people to the Royal Orthopaedic Hospital as there were so many patients with severe joint issues which had progressed to needing joint replacement.

65. I know that one of the co-infected patient's wives who wasn't at our centre, was qualified to do acupressure. Due to the small clinical space in our centre, we could not offer therapies like this to our patients.

66. We used to ask the Macfarlane Trust for funding for homeopathy and counselling. We made requests to them to obtain funding for both alternative and mainstream therapies to help the patients. The patients would approach us verbally requesting the help and we would apply for the funding on their behalf. Applications were frequent. Sometimes it was successful particularly in end-of-life situations but not so much where there was likely to be a steady, ongoing need for the service. That would cost money if a commitment was made.

**What information was provided to patients at the Centre before they began home treatment, and by whom?**

67. The Community Nurse would have gone out to see patients, and this would have been discussed in advance during clinic or clinic, MDT meetings. (Samantha Day and Jill Wilson were two of our nurses). When starting home treatment, the patient would be given a small amount of stock (maybe enough for 2 treatments) and then see how they would get on. They would be trained by the community nurse to inject themselves, monitored, supported and their use reviewed. We designed a leaflet to help but a lot of the patients already knew the information and what was required, from their clinic review with the doctor. Many people moved onto home treatment. The leaflet was a local initiative only.

**What was the Centre's approach and the approach of senior clinicians at the Centre, including Dr Jonathan Wilde, to obtaining patient consent to treatment and to testing? What information would be provided to patients and by whom? To what extent were decisions about treatment and testing taken by the doctors rather than the patients? Did this change or develop over time and if so, how?**

68. I was involved in consent. It was common practice, if not involved in a trial etc, to write the patients verbal consent in their medical notes. It was Unit policy and understood as such and it would be explained to the patient that their consent was required. As far as I know Dr Wilde enforced and encouraged this. Regarding treatment as I mentioned earlier initially this was the doctor's decision but gradually the patients gained more say in what they were treated with. All treatment would be fully explained to the patient including potential side effects and outcomes prior to obtaining their consent.

69. When vCJD was implicated in factor VIII products, there was a UKHCDO directive that if you wanted to know the batches of factor you had had, as part of the look-back exercise in respect of vCJD, then we had a specific form. This was how the patient consented. The form came from and was designed by the UKHCDO but was returned to the Centre when completed, as that was where the patient information was held.

**Was any training or advice or instruction provided to you at the Centre in relation to obtaining patient consent to treatment and to testing? If so, please describe the training, advice or instruction given.**

70. Doctors generally decided the treatment. When Recombinant came out in the 2000s, then patients started to challenge and discuss with doctors as to which products they wanted.

71. Some patients felt confident with plasma and argued to go back to it instead of Recombinant. There were occasions where the doctors would override the patients when it came to which product they would be on, UKHCDO had a national policy regarding Recombinant. They started off with babies and those who had never had other treatment and worked their way up in age bands with the objective of Recombinant for all. This would possibly have started about 2004. I think the doctors often looked at the finances short term instead of how patient's lives will be affected long term and the cost effectiveness of people not having joint disease in the future.

72. Regarding consent there was some training mainly within the Unit and it was the doctors who would normally gain consent to treatment and testing. It was their responsibility instead of the nurses. However, there may have been occasions when the doctor was called away or wasn't around or there was a time pressure and then the senior nurse would do it. There were Trust consent forms stored on the unit that I would use to ensure consent was completed as fully as it should be and the patient understood what they were consenting to.

**Were you ever told to withhold information from a patient or patients about risks, or treatment, or testing, or diagnosis, or their condition? If so, by whom and in what circumstances?**

73. Prior to the letter about potential vCJD infection, the first one being in the mid-2000s, we were told to not speak about or discuss it as the UKHCDO would be sending letters and information out. That's the only occasion I can remember. This directive came from UKHCDO probably to prevent misinformation being given. However, the patients had very good sources, and they often would know things before us.

74. When a patient had a positive diagnosis, I would let the doctor tell them. When I became more experienced and knowledgeable in the field of haemophilia, then I would tell the patients their diagnosis and go through the next steps with them and offer support..

**Was it customary to take blood samples from patients when they attended the Centre and for what purpose? What information was given to patients about the purposes for which blood samples were taken, and by whom?**

75. We used to see HIV patients every month, in order to monitor their blood count. We would keep their vaccinations status up to date. For example, for HBV and if they needed a booster. The patients would be aware of this from the doctor or even the nurse in relation to how their condition was to be managed.

76. As time went on, as clinical knowledge developed and so practice changed and we they didn't need to do a blood test every month, we didn't need to check their blood count if they were well. With advances in HIV testing focussed on viral load rather than CD4 counts and again this was reduced to every 3 – 4 months. Whilst before it was all about blood tests, this changed and a more holistic approach was taken looking at how the person was clinically and psychologically not just what their blood tests told us.

77. We did however begin to focus more on testing Factor levels to see what the recovery was following doses of Factor VIII or IX. This helped us to see how recombinant products were working and to ensure we had the right dosing regimens.

**What information would routinely be given to patients about liver function tests and the results of such tests?**

78. Patients would have the need for the tests fully explained to them, such as checking ALT levels. It would be the same if a biopsy was required. An explanation would be provided and consent obtained. People would ring up, in fact almost all of them did this to get their results. If not, they would be told on their next appointment face to face. Any abnormalities would be clarified with the doctors and would be discussed with the patient in person.

**Were patients informed if their blood was going to be tested for HIV, HBV and/or HCV and, if so, by whom? Did the approach to informing patients change over time?**

79. Yes, it would be whoever administered the blood test and it was always carried out this way. When I first started, partners of patients would have to sign a consent form to have a HIV test and it would be done anonymously recorded on the form as 'consort of HIV positive haemophiliac'. We would code it with the Regional
80. HIV number of the patient and the partners date of birth.

**What was the practice at the Centre about informing patients of test results (whether positive or negative or inconclusive) for HIV, HBV and/or HCV? Were patients informed of the test results promptly or were there delays in test results being communicated to them? How, as a matter of usual practice, were they advised of their test results (e.g.by letter, or by telephone, or in person at a routine appointment or at a specific appointment) and by whom? What, if any, involvement did you have in informing patients of test results?**

81. I'm sure at some points there were delays. People who were not overly concerned would not call in and instead wait for the next appointment but as I said above, many called in to check their results. They knew the turnaround times. I don't think we used the post very often unless it was difficult to get hold of a patient. Most provided contact numbers and you

came to recognise the numbers as well as the voice on the end of the phone due to the regular contact that was maintained.

82. Any abnormalities should have been given to Dr Wilde, but sometimes there would be a delay. For example, there may be 1 week waiting for the paperwork. Clinics were normally on a Thursday and if a result came in just after that it may be the following week before it was relayed. But if it was serious outcome, the patient would be called in to be told in person and for treatment to be discussed. That could have been by phone or letter depending on what contact options we had. A lot initially depended on the Lab staff bringing results to Dr Wilde's notice but things improved as computer systems came in and results were passed on more quickly.

**What information or advice was provided to patients diagnosed with HIV, HBV and/or HCV regarding the management of their infection including the risks of infecting others? How did this change or develop over time?**

83. There were always leaflets. But maybe not about HCV, when I started in 1995.

84. There were a lot of 1-1, face to face meetings, more so than leaflets and of course managing infection and safer sex was part of those talks. Managing infections advice was so important particularly in the early days when treatments were limited or non-existent. Mark, the social worker would provide support both at the hospital and in the patient's home. Further support would be given by the community nurse. Often Mark and the community nurse would do 'joint' visits. This could be in the evening or during working hours. They were very flexible and discreet. We had 800 patients registered with us overall and about 200 of those originally when I started, were infected with HIV, HCV or co infected with HIV and HCV.

**What was the practice at the Centre as regards testing and/or providing information to the partners and/or family members of people known or suspected to be infected with HIV, HBV or HCV?**

85. We would meet the person to be tested face-to-face, we wouldn't put a name on anything, it was all very secretive. Everyone would have a regional number for HIV positive and sometimes a date of birth to identify them. Partners would be identified as 'consort of'. Nobody would know, even the labs wouldn't know. Eventually the whole process became more relaxed and partners were happy to have their name on the forms and have a hospital number. Testing was offered to spouses but we didn't do it routinely, sometimes they would ask for the tests themselves before any offer was made. It wasn't a policy to routinely test them, but leaflets and literature were available to enable them to deal with risks and any problems. I believe that testing was mandatory before I arrived and it changed at some point. We also offered community nurse support, social work support (specialist social worker-Mark) and face to face support on the unit. Partners of course could also go to the local GU clinic and get a test that way. They did not have to get tested at the Haemophilia Unit.

**Was any form of counselling or psychological support made available to patients infected with HIV, HBV and/or HCV or to their families? If so, please detail what support was available.**

86. Yes, eventually, Dr Ann Bond, Bobby Read (Clinical Nurse Specialist for Psychology) and Mark. I would also support patients with psychological support as would the Community Nurse. Mark and I would also apply to the Macfarlane Trust for private counselling when the need arose normally making those applications on behalf of clients – although they could make the request direct to the MFT but this was rare. There was support given although it did take time to set up and as time passed each request took longer to get approved. Prior to this

I believe it was only the Clinical Nurse Specialist who would provide the service. There was a psychiatrist available on a rolling monthly basis and they would provide what was called Liaison Psychology.

**Was any form of social work support made available at the Centre to patients infected with HIV, HBV and/or HCV or to their families? If so, please detail what support was available.**

87. Yes, Mark Simmons was a full-time specialist, social worker attached to the Unit. He started about 1998 until 2017. He dealt with the Haemophilia sufferers and was an expert in his field assisting with benefit enquiries, debt advice and providing counselling and support as well as many other aspects of care. They may not have someone in that role now. Before his time, it would be a case of referring them to the local department. Prior to Mark there were social workers attached to the unit but they were general social workers and were part time and did not have the specialist knowledge or experience of supporting people with blood borne viruses.

**Please describe your working relationship with Social Worker, Mark Simmons.**

88. We are still very close now. We had a very honest and open working relationship. We were each other's support in what was a high-pressure job most of the time. We would bounce ideas off each other. I think we worked really well together. I think the patients felt we worked really well together and would often ask us for a joint visit. This was the same for some of the haemophilia community nurses.

**How was the care and treatment of patients diagnosed with HIV, HBV and/or HCV managed at the Centre? What treatment options were offered over the years to those diagnosed with HIV, HBV and/or HCV? What follow-up and/or ongoing monitoring was arranged? To what extent were patients at the Centre referred for specialist care elsewhere? How did any of this change or develop over time?**

89. When I started, we used high purity Factor 8, there wasn't much choice for products for haemophilia. There were very few drugs at the time for HIV. When new and more expensive drugs came in, such as protease inhibitors, the unit had to put a case forward for these more expensive drugs. This was normally to the West Midland Regional Health Board. It was horrible trying to say someone should get a certain treatment over someone else. It has never left me seeing a 20-year-old die through lack of a possible treatment because of fighting for him to be funded to have the drugs. It never leaves you.

90. AZT was the main and only treatment available for many years. In time we then had Protease Inhibitors, but they would cause abnormal bleeds, soft tissues bleeds, which were very odd bleeds to deal with. One of the new drugs introduced was called 'Ritonavir'. Initial full-strength doses caused some serious bleeds in our patients but gradually with experience and time it was realised that a lower dose (300mg down to 100mg if I recall correctly) when used in combination therapy, proved very effective. The lower dose of ritonavir acted as a booster for the other HIV drugs and was hence more affective in suppressing the HIV virus.

91. T20 injections which was a trial therapy initially, would cause horrendous bleeds, but as a salvage therapy I do believe it saved one of our patients lives as I was told it had. I think he was prescribed it at Chelsea and Westminster. Certainly not through us.

92. We had no-one who was infected with HBV that I recall. There was a vaccination for it and HAV and it was in the past the main infection. We did have one patient that was a carrier.

93. In 1998, HCV was treated with Interferon alone and then in combination with Ribavirin. This was the trial I mentioned before. There were strict criteria for acceptance although some patients did access it on compassionate grounds Combination therapy with Ribavirin and Pegylated Interferon produced less side effects than before but still horrendous for some. As time progressed it was clear to the drug companies and medics that using combination therapies was better than simply using one drug. The trial was opened by Dr Phil Shields at the QEH and the company involved was Roche.

**Do you recall patients diagnosed as HIV, HBV and/or HCV positive being treated differently to others? If so in what respects? What if any measures were implemented to address any risks of cross-infection?**

94. If someone had to have surgery, they had to be the last surgery on the list for that day. This was to ensure the theatre was thoroughly cleaned down and made sterile afterwards and to reduce the risk of any cross contamination. This was normal for any infection. When I worked as student any person that had any kind of infection was last on the theatre list.

95. Sometimes you had to fight for the patients, there was stigma, a lot of stigma at times. They would be treated differently sometimes by some staff members outside the Unit but this was just a fear of the unknown for many. I have challenged this as I've mentioned but it comes down to a lack of education, even amongst doctors and nurses. Within our Unit we aimed to treat everyone in the same manner.

96. Blood forms would be labelled with a 'biohazard' sticker on the blood tests. HIV related tests originally had a sticker and then it became so normal, and routine, it was removed. HCV got the sticker treatment as well when it first became a known. The forms were all printed with biohazard signs anyway so I don't know why they needed extra stickers.

**To your knowledge, were clinical staff made aware of patients' infected status in relation to HIV, HBV and/or HCV?**

97. Yes, in their notes. We also had a card index section in case our notes were misplaced or were somewhere else. There was no sticker on these cards but their infection status was shown.

**Please describe as fully as you can your involvement in the treatment and care of those who were infected with HIV, HBV and/or HCV and what you can recall about the impact of the infection(s), and/or of treatment for the infection(s), and/or of the stigma associated with the infection(s), upon them and upon their families over the years.**

98. The group originally would not go to the GU unit because they were upset about how they were infected and didn't want to be with those that were infected by a different route due to the prejudice and stigma attached to HIV, it was all very secretive, everything was coded. You need to remember that haemophilia is an inherited condition and so cousins and family members would be at the same clinic appointments so if they attended the GU clinic it would be clear they were infected with HIV. We had a lot of people who died of HIV, and later of HCV. As the stigma was so lasting, relatives often asked for any mention of HCV or HIV to be removed from their death certificates. Instead, it was written that they died of the HIV or HCV related cancer or immune-compromised conditions. The drawback was that it meant the family couldn't prove later down the line that their relative had died of HIV or HCV infection when there was compensation or the ex-gratia payments. I assisted families and patients when required and where it was possible, with blood results and similar from the patient's notes that would help the families prove their loved one's infection.

99. I supported people at the end of their life, also to apply for benefits, counselling, as in counselling after their loved ones died.

100. Macfarlane Trust implemented a review to look at where the funds they had would be best spent in supporting the people infected and affected by HIV. This included meeting with the widows. Mark and I advised the Trust to provide some form of psychological support for the staff meeting with these people as we knew that their stories would be upsetting and difficult to hear. We were also very concerned that for some, especially the widows, reliving these stories and taking the 'lid' off with no support to deal with these traumatic memories afterwards, would be very detrimental to their mental health. Making promises of financial support was not the way forward. As it was it did cause a lot of anguish for many of the widows reliving what they and their husbands had been through. As predicted the study found there was more need than there were funds to support these people. I don't know if anyone received any monies in the end as a result of the review. I know there was around 3 million in the bank and that primary beneficiaries were approached with MFT staff going out to see them to obtain ideas but it was wrong as hopes were raised and then nothing much came of it.

101. Some patients did suffer from the side effects of treatment and medication particularly with the early drugs. With HCV, Interferon was particularly harsh on some of those who received it.

102. We had a women's group for wives and mums, for those infected or affected HIV and this was well received.

103. In my role I felt that I gave a lot of psychological support. The other nurses would look after the Factor treatment.

104. I saw a patient who was around 20 years old, he just couldn't cope with his diagnosis, he was co-infected and in effect, drank himself to death and he died of liver failure due to the alcohol. He was a young lad whom we spent a lot of time with and tried to support him, but it was too much for him. It was so difficult to watch knowing there was little you could do.

105. We had people who were suicidal. I don't recall any actual instances where people took their own life but certainly some were close to it. It was more self-harming that affected them such as not taking their medications, alcohol misuse, drug misuse, not treating bleeds.

**Section 5: Research**

**Please detail any knowledge you have of any research that may have taken place at the Centre including the names of clinicians who were involved in or leading the research.**

106. The trials of Interferon by Dr Phil Shields. I believe the company running the trial was Roche.

107. The doctors used to do research as part of their studies.

108. Octapharma, which was a Swiss company, had a blood product for Von Willebrands called Wilate, and I remember there was a trial carried out with their product.

109. I'm sure we took part in trials for running factor VIII continuous infusions. As this was mostly for surgery and most of the surgery was at the Royal Orthopaedic Hospital, the Community Nurse would go and set up the infusions and record the information for the trial

110. We had many patients with only a small number of staff. We didn't engage in many trials. We had no research nurses attached to haemophilia.

111. Before I left, we were trialling some gene therapy.

**To your knowledge, were patients made aware of their being involved in research? What was the approach taken with regards to obtaining their consent to such involvement**?

112. Yes, they would have to consent. This would have been written consent normally obtained by the doctor overseeing the trial. CRF's were comprehensive consent forms with withdrawal clauses if the patient felt uncomfortable.

113. For the look back study in about 2004 we wouldn't have asked for consent. This was a study not a trial. It used anonymised data.

**What does the term 'PUPS', an acronym for a category of patients referred to as 'Previously Untreated Patients', mean to you? Was the term used at the Centre and if so by whom and in what respects?**

114. To me, mostly involving children, because we didn't have children in our Unit it was not a term used very often.

115. We had very few PUPS on our unit. Possibly this could be used in relation to those who used desmopressin (a synthetic injection, which boosted clotting factor). If the desmopressin became contraindicated due to health or age, we would then automatically use Recombinant factor when it was available, (for those who had never had blood products before). Also, recombinant would be the first choice for those with mild haemophilia who were only diagnosed later on in life.

**Section 6: vCJD**

**Were you aware of the risks of transmission of vCJD associated with the use of blood and blood products? If so, when and how did you become aware?**

116. I wasn't until it was in the news. I was away when the letters went out. There were so few infections so I am not sure if I found out via the news or the consultants at the unit.

117. I believe there was a male haemophiliac patient who had the prion. They were found to have vCJD in their brain, post mortem, although they had no symptoms when alive.

118. I remember lab staff telling me that the labs were aware of CJD as early as the 1970s. I don't know if this was vCJD or not.

**What was the process at the Centre for informing patients about possible exposure to vCJD? When and how were patients told of possible exposure to vCJD?**

119. We had a special letter, and a special clinic. We invited patients in. There was a theoretical risk calculator. It was more about "do you want to know if you were exposed?". A lot of people said "no, don't tell me, even if I had an implicated batch". This was hard for them as many could have more than one letter, potentially. This was yet another hammer blow, being told multiple times they could have been exposed to yet another possibly fatal infection, so eventually lots of the patients chose to stop being told.

**What information was provided to patients about the risks of vCJD?**

120. Basically "do you want to know? There is minimal risk at the moment as we have very little information." There was not much known. It was a case of wait and see. Also told it was a theoretical risk and no test for it...

**What counselling, support and/or advice was offered to patients who were informed that they might have been exposed to vCJD?**

121. Me and Mark really. The doctors had a chat in clinic, that was it at the time. There was nothing in place and most knew nothing could be done about it anyway.

**Section 7: Effect on clinical staff**

**If you haven't already answered further above, how did the Centre's practices change over time to reflect the risk that HIV, HBV, HCV and vCJD infections posed to clinical staff?**

122. Just universal precautions. Wearing PPE, always make sure you used it regardless of if you knew a person viral status or not and this way everyone was treated the same. We had many patients who were being cured of HCV and becoming virally suppressed with the HIV treatments. You could see the progress being made medically. Post-exposure prophylaxis for a needle-stick injuries was available from A&E if required. We were all vaccinated against HBV.

**What was the Centre's protocol for reporting concerns or complaints about staff and/or patient safety? Did you ever report any concerns or complaints? If yes, who did you report these to?**

123. I was always reporting if I wasn't happy with something. You go through your line manager or supervisor and it goes up the chain. Everyone was aware of how to lodge a complaint. Once, I was told off for complaining too vociferously about plans for the haemophilia centre. We only had 2 rooms for our clinic as it was, and they wanted to take even more space from us. I was always in trouble stating my opinion about this but we did eventually get the centre and the space that was needed. Depending on the nature of complaint, for something say, that was health and safety related for example, I may go direct to the head of that department.

124. I would report other things like, an ambulance couldn't get through the gates which were locked when they shouldn't have been. Patients could not access their treatment safely and quickly. This was a daily issue, and someone has to tackle these things, or they get worse.

**What impact did treating haemophilia patients who subsequently contracted infections from their treatment have on you both personally and professionally?**

125. I think this was one of the reasons I left, I was exhausted by it. It's a lot of absorbing people's pain and suffering. I was also was tired of fighting to keep the centre where it was, you're taking on the senior team, the finance team, resources are few and many are competing for them.

126. I felt privileged that I could be with my patients but when some of them died, certain deaths did shock me. It's harder when you aren't prepared, when you see a patient who finally got their life back and then they die. You have been with them on a journey of sorts, sometimes

for a long time and it is heart-wrenching. It's like a family but with boundaries. I still have friends there.

127. The politics of the NHS got so complicated. People kept coming to look at how I used my rooms and facilities and then they wanted the cancer patients to move in. There was also the paperwork, mountains of it. I think I was probably burnt out, before I left. The nature of the service was changing. The patients who I'd looked after with HCV and/or HIV were generally well and able to live a life and I didn't want to be part of a centre where haemophilia became second to thrombophilia and general haematology side of the specialty. I knew once Dr Wilde retired the unit would change in nature and this wasn't for me. Even though the new consultant was a Haemophilia Consultant, it was clear that things were going to change and that the service would have to incorporate more conditions that weren't haemophilia related.

**Section 8: Trusts and Schemes**

**Were patients at the Centre provided with information about, or assistance with, any of the trusts and schemes that were set up to provide financial assistance to people who had been infected (such as the Macfarlane Trust ("MFT"), the Eileen Trust, the Macfarlane & Eileen Trust, the Skipton Fund and/or the Caxton Foundation ("CF") (the Alliance House Organisations (AHOs))? If so, what information and/or assistance was provided?**

128. Yes, Mark and I were constantly going to these funds on behalf of patients. Mainly Macfarlane, Caxton, and Skipton. Mark also dealt with The Eileen Trust for HIV related requests. Patients were made aware of how to apply themselves and there was some literature about what was available displayed at the centre.

129. Not everyone would know how to apply for the funding or have the confidence and ability. The community was quite proud and didn't want to ask for money as they felt they were going 'cap in hand' when they were told it was set up to support them. Some were better at using the system than others. Patients and their relatives did not feel they should have to have every aspect of their lives inspected to get some monies.

**Please describe any involvement you had as a Clinical Nurse Specialist in assisting patients with their applications to any of the AHOs.**

130. You had to write an e-mail to justify why you wanted the grant. It was almost always me from the nurse team, (or me and Mark) who wrote on behalf of my patient. We had to explain why they needed this funding, show quotes and the impact on their quality of life that the granting of funds may have. I made more applications than I care to remember. The patients themselves would simply call us if they wanted to apply or it may come to light in a visit to the centre. As stated earlier very few went direct although there was a mechanism for that. I think it was too daunting for many of them.

**Please describe any other involvement or dealings that you had with any of the AHOs, and provide your response to the following questions, if you are able:**

**What did the application process for those infected or affected to any of the trusts and schemes entail?**

131. Typically, just me or Mark, I would e-mail and the Trust would ring me back. There was no online application. It just depended on who you got on the phone. To me it was a subjective process. To me, the trustees themselves were probably financially stable so couldn't understand the position the applicants would be in. I feel there was a lot of judgement. There

were some fantastic people there initially – I remember Roz, but they left. Some patients were given the funding. There were discussions that patients had been given compensation or funding but then they were seen to have 'blew' the money. There seemed to be little understanding or compassion that these were the same people who had been told they would be dead in 2 years and not be able to go to uni or do much with their lives!

132. Patients could actually make an approach on their own without assistance and I am sure many did.

**In your experience, were the application criteria for applicants transparent and accessible?**

133. No, it would change every single time. Another hoop to jump through was often introduced. Nothing was simple.

134. There were some people who would apply for a pair of trainers. Then there were some people who would be at their end of life, or their husband was dying, it was hard. For people with life limiting illness there was a form called a DS1500 which was a fast track which had to be filled in by the Dr and should have allowed people to fast- track services e.g. if they needed equipment in the home. Even with a DS1500 it could take community services some time to provide equipment. Time the person didn't always have so we approached the MFT for urgent support. For example, a bed could be in the patients home within 24 hours if funding was agreed quickly. It would be successful most times. Roz who worked in the Trust was very helpful to us. But when she left, it was harder and harder. She would guide us in our wording and "if you write this and write that; then it should be successful." Let's just say there was a way to write the application to get it approved and not everyone knew it.

**Did any of the AHOs require repeat applications to be made for financial support? If so, was this necessary in your view?**

135. Sometimes. Yes, in a way and it would depend on the type of support requested. Generally, an application would not go in unless it was really necessary. As we worked on the ground we could see when it was really needed and I feel we were in better place to make a judgement The trusts had the money but they were quite detached – they had no idea about how those suffering were actually affected and I feel it was all about figures and costs for them.

**Was practical support and assistance provided by the trusts and schemes to applicants when making applications? If so, was it sufficient in your view?**

136. No, there was no direct help. Mark and I would try to provide support and often would complete and submit the application on the person's behalf. However, I don't think it made an ounce of a difference in the majority of the cases. I remember Mark would tell me, "I know they have extra money in the funding". We just could not always access it.

**What, if any, observations do you have about the decision-making processes of the AHOs when considering applications for financial support?**

137. Not consistent at all and they were judgemental in the decisions made or so it seemed. By that I mean that some people were refused requests that others in the same position had been granted. I believe that our application style was recognised and this allowed the trustees to possibly identify who the application referred to and there were some who asked for more than others – only because they needed more in most cases, but I think judgements were

made on this basis and often those same applicants would be asked for additional evidence to support their request.

138. Eventually the patients became so demoralised, they felt like they were begging and eventually they said "I don't want to beg." They let it drop and this seemed to suit the Trust.

**How were applicants to the AHOs treated during the application and decision-making process?**

139. I can't comment on how those dealing directly with the MFT and how they got on but we (the haemophilia team) would often ring Roz at the MFT and try to keep an eye on the process or find out how far a request had got. Caxton was the worst I felt that they would often just stonewall us. It could take ages to get a reply – it's too long ago to give specific examples but applications around respite care and psychological support stick in my mind as being the most difficult to get an answer on.

140. **In your view, were decisions by the trusts and schemes made in an efficient and timely manner**?

141. Not really. Things seemed to be slow considering the state of heath of the people making the request and their often, urgent needs. Maybe they needed more funding for staff. I can't put a time on any individual request but nothing was quick.

**How did the trusts and schemes approach urgent financial assistance requests?**

142. If someone was about to die, they would be a bit better as it was a one-off request.

**Were applications decided in a consistent manner? If not, please describe any inconsistencies you are aware of.**

143. I would say no but it's difficult now to recall individual examples. We got so good at the emails with the 'correct' wording. I think they worked out the who the emails were from and knew who (which patient) was asking for funds – each patient had a Primary Beneficiary number - and this worked against us at times. The other problem was they did not seem to realise that some people needed more assistance as they got older. Their requirements became greater and more frequent but the Trustees did not seem to understand that.

**In your experience, were adequate reasons given by the trusts and schemes when applications were refused**?

144. You would always feel like an application was genuine when you supported or made it. The request was rarely just a general need but mostly a necessity. They didn't really give reasons. People would follow the process and send the quotes. So, we did everything that was required only to be turned down. We knew they didn't have a bottomless pot of money but there were very rarely reasons given.

**What, if any, information were you required to provide to the trusts and schemes in support of an application for financial assistance?**

145. We had to supply quotes. We would note the request if the applicants were providing funds towards the request themselves (the patients), what the issue was and the benefit there would be for the patient. You had to show there was a gain to have any chance of funding. Then the Trust started asking for income and expenditure forms from the patients. This was

very distressing for many, who then stopped asking for support as they felt this was a massive invasion of their privacy.

**In what type of circumstances, if at all, did you ask the AHO's to reconsider any decisions they made regarding applications for financial assistance? You may wish to consider [MACF0000146_058] when providing your answer.**

146. **MACF0000146_058,** I remember this one, he was rejected, I tried to put pressure on them but they didn't change their mind. This would generally be by making contact by email or telephone and pushing the case as best I could or perhaps looking for further supporting evidence to submit.

147. Often, they would say "not enough evidence" etc when you asked for a reconsideration.

148. They would be more likely to choose to pay for a practical request over say, a counselling one. They would choose the cheapest option If something was expensive, they would always push back.

**Please describe your working relationship with MFT support services officer Keisha Hanchard.**

149. She was new, GRO-D . I felt she came across as pleasant enough, but she was pretty rigid in her outlook. I think she was under a lot of pressure from the Trustees. Unfortunately, I can't recall any of their details.

**Please describe your working relationship with MFT support services officer Rosamund 'Roz' Riley**.

150. She came across as a caring and interested person. There was a lot of pressure, so she left. I think the Trust thought she was too lenient and not critical enough of the applications. I think MFT brought someone in from the outside, Jan Barlow, she came from another charity I believe, to 'sort things out' and that may have led to Roz leaving as the staffing changed.

**Please describe your working relationship with the Caxton Foundation welfare officer Nicole Hornby.**

151. With the Macfarlane Trust, initially you could get stuff through. Caxton was very different. They would examine cases very thoroughly. They wanted receipts for everything and it was often very drawn out. I wasn't very successful with them but I don't know about Mark. I personally may have sent emails to Nicole but contact with her was limited and t I don't recall much conversation or interaction.

**Please explain your working relationship with the MFT Chief Executive Martin Harvey.**

152. I got on reasonably well with him. I met him a few times. I recall he told me; "You and Mark really care, it's clear it comes from the heart but for me this is my job."

153. He still cared though. If you saw him face to face, or called him, you could talk to him and he would often listen and try to understand where the applicants were coming from which was not the case with some of the others. He would sometimes meet with our patients face to face and listen to their concerns. There were occasions when he overturned a refusal.

**Macfarlane Trust ("MFT")**

**How frequently did you assist beneficiaries by writing letters of support for financial assistance to the MFT? You may wish to consider [MACF0000100_010], [MACF0000100_018] and [MACF0000100_021] when providing your answer.**

154. All the time initially. There were always requests from patients for help with applications. Each one would take about 20 minutes when I got good at it. At first it was difficult as you needed to know what they expected to see on the form to make a decision and hope it was a favourable one. But eventually they weren't parting with the funds. It slowed down over a few years and became a real fight and difficult to get anything through.

155. **MACF0000100_021 -** He was co-infected and he used to buy cars. That was his way of coping. The loan he was granted was secured on the family house. He died from HCV. Mark had fought really hard for it not to be secured against his house as this was very unusual. People were usually given a loan but not against their house.

**How were the letters you wrote in regard to requests for financial help received by the MFT? You may wish to consider [MACF0000015_026] when providing your answer.**

156. Initially very well. We were successful with most applications. But then they seemed to pick up on the style of writing and they started to say no. I think in the end it prejudiced us. The Trust knew that we were providing assistance whereas earlier on they did not. They also were able to identify the number of applications made by some clients and looked at this rather than the reasons for the application.

**Were any particular types of application that you provided a support letter for (for example counselling, mortgage arrears, fuel and heating costs), more or less likely to be met with success? You may wish to consider [MACF0000015_026] when providing your answer.**

157. No, there wasn't one type of request that was more successful than others. I believe that it just depended on them and how they saw it on the day.

**Please explain how you came to be involved in MFT events such as the Women's Day for MFT beneficiaries in May 2006 [MACF0000116_051] and the Cardiff One Day Therapy Event in March 2010 [MACF0000015_078]. How were such events received by MFT primary beneficiaries?**

158. Originally, we asked for the MFT to fund a Women's Day. The idea was Mark's and mine. It was to provide support for what we thought was a forgotten group. The money was used for the meeting room at the hotel, and the ladies also had a meal. We organised this. It was a lump sum of money and it enabled us to get some therapies too on the day. Dr Ann Bond was there and provided support and counselling to the attendees.

159. There was another one-day event in Cardiff, (funded by the MFT) with a lady called Pippa, I don't know her last name, who was there providing acupressure and other therapies. The event was for infected and persons and families affected by HIV (positive haemophiliacs). The events were really well received and when funding was available, we tried to and did run more of these types of events.

**In letters to the MFT from you dated 24 August 2005, you make an official complaint relating to the handling of a case [MACF0000101_087] and in a further letter dated 19 December 2006 [MACF0000099_054], you express concerns about the MFT basing decisions on the previous application history of a registrant and highlight how a patient in the end stage of their disease would need greater support rather than less.**

**Did you receive responses to your letters of complaint** ?

160. As soon as I got up to speed on what they wanted (how the requests should be written) then they would change the requirement or level of 'proof' needed to get an application through again. I can't remember ever receiving a reply to this complaint.

**If so, did they address your concerns?**

161. No. Probably got worse with time as well.

**In your letter dated 23 November 2004 to MFT [MACF0000107_010], you state that you wanted to 'ask when policy was actually changed as we have had no notification of this'. Did the MFT take any action to ensure you, Centre staff and primary beneficiaries were kept up to date with any changes in policy? If yes, please explain how.**

162. I would say they informed the primary beneficiaries probably in writing. We did not get notified in our role when changes happened, more often finding out during an application process, Sometimes, we would find out about a change from the Primary Beneficiary themselves. I do not recall any information on policy changes being sent to the centres either. I don't think the policy was generic. For example, there were changes to the rules about respite. Before people could have respite breaks from time to time, you could at least get a break. Later, at some point you couldn't get a break even after having been in hospital as the criteria changed and people didn't know. There were plenty of unsuccessful bids for assistance.

**Did you ever assist applicants in appealing decisions resulting from MFT changing its policies without informing primary beneficiaries and Centre staff? You may wish to consider [MACF0000135_004] when providing your answer** .

163. Yes, I helped them. But I tried to help with so many that I find individual instances hard to remember. The changes meant there were lots of appeals as peoples fought to try and get the help they needed – sometimes help that had been there before that was now denied. We, Mark and I would try to enhance their application, stress the urgency of the need, possibly get a medical opinion if it was available or supporting evidence from another partner such as the local authority. We would also ask the MFT what they actually wanted from the applicant.

**In your view, was the MFT consistent in the application of its policy for respite breaks? You may wish to consider [MACF0000107_010] when providing your answer.**

164. They were inconsistent in my view. It got worse and worse. Eventually for respite breaks, they chose the places as official respites which were approved, instead of, for example, a patient might choose a Caravan holiday. It was often very expensive funding a stay in a designated respite place rather than the cost of respite where the person actually wanted to go. There were some patients and applications where they did initially say yes to their funding request only to eventually turn them down.

**In your view, was the MFT consistent in the application of its policy for 'moving/setting up home' grants? You may wish to consider [MACF0000130_002] when providing your answer.**

165. Initially they were quite good. If someone needed money, say for white goods for example and they wouldn't help, then we would ask under the banner of 'moving/setting up home'. They were better at saying yes to these requests. Sometimes we had to use these

methods of playing one fund off against another to achieve a result. They were quite consistent with that one.

**Were there any noticeable differences, in your view, between:**

**The success of applicants securing a loan versus a grant from the MFT? If so, please provide details.**

166. It depended how they would secure the loan, for example against their home. We would always say don't do it. Mark dealt with this side more than me. I didn't deal much with this. Loans were easier for them than a grant as it didn't ultimately cost the Trust.

**The quantity of appeals for loans and grants you were asked to support? If so, please provide details.**

167. If they said no, we often just appealed it. If a grant wasn't available, then it would have to be a loan as the people asking had a need for the money. I can't quantify the number of appeals but there were definitely more as time went on and more and more initial requests were refused.

**When supporting applications for MFT funding, you have, on occasion, requested decisions be revisited due to the case being 'exceptional'. How did you determine 'exceptional' for these purposes? You may wish to consider [MACF0000113_013] when providing your answer.**

168. We didn't have any criteria. There was never an explanation or guidance on what would be considered 'exceptional'

169. There were no 'exceptional' criteria as such from our viewpoint This was just extra effort trying to get help on the patient's behalf where we could see they really needed it. In the instance given we even put the effort in to travel and plead his case in London at the Trust, but it was still unsuccessful and we didn't know why. Sometimes we would ask what more does this person have to have wrong with them or go through for it to be classed as exceptional. In the example, the person was a full leg amputee and was still trying to work and asked for a mobility scooter and wet-room to be funded to make their life easier, yet it was declined despite all our efforts.

**Did you have any guidance criteria to help you determine which applications should be reconsidered? If so, who from? You may wish to consider [MACF0000099_054] when providing your answer.**

170. There was no real criteria or guidance to help which should be reconsidered. Often it was a judgement call from us or where you could see the need was, at times desperate or where the patient wanted to retry, having been refused but didn't know how to appeal. There were plenty of them.

**If you did not have any guidance criteria to assist you in determining which applications should be considered, please explain in what circumstances you would send a request to MFT to reconsider an application.**

171. Anything we felt was unjust or where you could see the need was pressing. Mostly the applicants would lose faith and get very down, but we would push for the appeals. After all, people didn't want to go to all this trouble unless it was to get something that helped them with their condition or that they really needed. Many felt they were being treated as worthless and

didn't see the point of pushing it. We would add more personal details, try to highlight the actual need and then we would still lose the appeal, so it was very hard. Very deflating at times. More so when you were aware that others had received the support in similar circumstances.

**Please comment on how frequently and in what circumstances you were involved in appeals to the MFT, how successful you found these appeals to be and how you found any appeal process. You may wish to consider a written request to appeal a decision taken by the NSSC not to award a home decorating grant [MACF0000186_026] when providing your answer.**

172. Some appeals would be successful but often they would get less funding than the original request asked for. And we would help at the applicants request or where we could see a pressing need that had been ignored. Sometimes, the MFT would agree to pay half or a portion if the applicant couldn't pay the full amount for an item or a respite break or something else.

173. I have been asked this earlier and didn't want to quantify but would say we appealed maybe 30% of applications. 5% of appeals were successful and would actually get a result after being appealed.

**Caxton Foundation ("CF"):**

**How often did you assist beneficiaries with applications to the CF by writing requests for financial assistance?**

174. Less often than MFT I would say. Psychological support and respite would be the main things. They were quite a closed shop and not easy to deal with. We would ask for fewer things and for cheaper things, like counselling. There were fewer requests, as people passed away and as time went on. It was seen that people were or should be more financially well off with Skipton pay-outs. It made a difference to some.

**How were the letters you wrote in regards to requests for financial help for beneficiaries received by the CF? You may wish to consider [CAXT0000088_017] when providing your answer.**

175. Mostly not having any of it, I felt that they didn't see the bigger picture or impact of lifelong infections on these people.

**Were any particular types of applications that you requested financial assistance for more or less likely to be met with success? You may wish to consider [CAXT0000088_017], [CAXT0000062_104] and [CAXT0000062_103] when providing your answer.**

176. It was just inconsistent. When they brought up the income and expenditure forms, we would always have to have the expenditure above the monthly income. It was all means tested and there was no leeway.

177. Skipton were good at helping with counselling, MFT you could speak to at times at least to put a case but Caxton, they never really answered.

**Were there any instances where you raised a complaint with the CF? If so, please explain:**

**the nature of these complaints;**

178. No, not a formal complaint but I would ask them on occasions to explain their decisions.

**whether the CF adequately responded to these complaints** .

179. No, it was always; 'we refer you to the conditions that need to be met' which we were not really aware of. Nothing was given in writing that I remember.

**Please explain if you had any concerns with the operation of the CF. If so, please explain:**

**Whether you shared these concerns with the CF;**

180. I don't think I ever officially shared them, but I did on calls when I could get hold of someone. The criteria were too strict.

**If you did share any concerns with the CF, please set out the CF's response to your concerns**.

181. Just repeat notification of the refusal with no explanation Nothing in writing as mentioned and referred to the criteria that needed to be met for a successful claim.

**Did the CF provide you with any guidance criteria for making assessments of beneficiaries in need of counselling? You may wish to consider [CAXT0000048_025] when providing your answer.**

182. The criteria were that any counsellor had to be registered and have a charter as a counsellor. But this still didn't mean you got the grant. There were guidelines I'm sure, but they were fluid and we never saw them. Often, the word 'exceptional' referring to circumstances was used and I, on many occasions, tried to get what this meant clarified by the Caxton Fund but without success.

**Did the CF provide you with any guidance criteria for making assessments of beneficiaries in need of financial support? You may wish to consider [CAXT0000062_104] when providing your answer.**

183. We knew about winter fuel payments from MFT as shown in this example but it was a payment required outside of that to tide the claimant over. As mentioned, there were no criteria provided by Caxton. There may have been guidelines but I don't remember being given them. This was an extra payment he needed at the time, on top of his funding from the MFT, to help with fuel costs they had already met.

**Do you recall sending requests to the CF to 'fast-track registrants'? If so, how did the CF usually respond to these requests? You may wish to consider [CAXT0000104_046] when providing your answer.**

184. Probably yes, towards the end of someone's life. People were often struggling psychologically, not just the patient but the families around them. With Caxton I don't remember it being great.

185. In the example, they sent him an income and expenditure form even though he had a DS1500, he couldn't cope with filling it in so asked for our help. He was dying of liver cancer

and she (his wife) had breast cancer. The £200 grant was declined because he wouldn't fill out an income and expenditure form. However, you never would know if you would be successful even if you did fill the form in. it was hit and miss.

**Were you involved in assisting applicants in appealing their decisions to the CF? If so, please comment on:**

**How frequently you were involved in appeal applications to the CF;**

186. I did get involved in some but not too many.

**In what circumstances you were involved in appeal applications to the CF** ;

187. Speaking to them via phone normally at the patients request to try and emphasise their need. It was limited to stressing their needs and on occasions as said earlier we could maybe get additional evidence such as medical or utilise the services of an occupational therapist to do an assessment to enhance the application or appeal. I recall we had a lady called Kay Harries who was an occupational therapist, that we used.

**Any guidance criteria you were provided with to help you determine which applications should be reconsidered. If so, who was it provided by?**

188. None.

**How successful you found these appeals to be;**

189. Not many were successful, only a small percentage.

**How you found the appeals process?**

190. So difficult. Very unhelpful. There was no consideration of the sometimes exceptional or difficult circumstances of the people asking. Although I don't remember that we were given guidelines to follow, they seemed to have them, and they were strict. I felt that decisions were arbitrary and there was no compassion.

**Criticisms/Complaints of the AHOs**

**How often did you receive complaints, if at all, from primary beneficiaries that the trustees of the AHOs were letting them down financially? Was anything done to rectify this? If so, by whom? You may wish to consider [MACF0000148_004] when providing your answer.**

191. All the time. A lot of people didn't want to do the income and expenditure forms, as this was a fund which was supposed to help people who were infected. Many felt it was prying and that they did not want to go cap in hand. There was inequality; some people got the money, and some didn't. Widows in particular weren't looked after. MFT was set up to only last a few years as I think the government thought everyone would die. They didn't think they would have to support anyone for such a long time.

192. We spoke to the schemes directly to voice concerns but I think it became like talking to a brick wall. We spoke to local MPs, went to the Houses of Parliament. We would put in complaints. They became more restrictive. The money in the pot could have gone to the

beneficiaries but it didn't. It seemed to be just sat there. There was the odd person, like Roz who helped us and would take on our complaints but real help and change was absent.

**Non-financial support to infected/affected individuals**

**What other non-financial support did the trusts and schemes provide to those you assisted? Was it sufficient in your view? Was there anything else needed? If so, what?**

193. There were a lot of groups who missed out, like the widows as I've mentioned. There was no support for them. We know that money isn't the answer for everything, but some people were stuck in a benefits trap. Even working a few hours was detrimental to them financially meaning they would lose money but, even a few hours of work had such a positive impact on their self-esteem and mental health. Some people had support from Skipton and MFT, but then that meant they would have to be very unwell to qualify for further assistance. There was so much inequality. A lot of centres had no one who would push it forward. That is why Mark's name would be renowned around the country for the work he put in to support them. We had a book listing all the charities in the country, such as the Ex-Servicemen Association and would often try these avenues for help when refused by the Trusts but in a way that relieved them of what was their responsibility.

194. More support was needed at the centres. There was a Haemophilia Social workers group but there were only 3 qualified specialist social workers in the country.

195. More regular payments would have been helpful without the hoops to jump through. There is always a limited pot of money and people understand this but some of the decisions made were disgraceful.

196. We used to get the prescriptions for our patients free and we would write 'do not pay' on their prescriptions, for the hospital pharmacy. The hospital probably got annoyed at me as this was unofficial. I just tried it and it worked for a while. HIV patients were on free prescriptions initially and then, slowly, haemophilia patients and then the rest.

**Section 9: Other Issues**

**With reference to [RHAL0000978_019], please set out the extent of your involvement with:**

**The Haemophilia Nurses Association Steering Group;**

197. I was only part of it for a short while. We looked at training for the nurses attending and developing the Haemophilia Nurses Course as well as organising the conference mainly. We were concerned about people who had cleared the various infections and whether they would be paid by the Trust or funds.

**The Haemophilia Nurses Association Hepatitis C Working Group.**

198. No, I wasn't on it. I believe they wanted to set up a course for nurses to understand it better, but I don't know if they ever did.

**What was the remit of the groups mentioned at question 79? Do you consider them to have fulfilled their manifesto? If not, why not?**

199. No idea.

**What were the retention policies of the Centre in regards to medical records during the time that you worked there?**

200. We didn't destroy anything. So, if families came to ask for access to medical records when applying for compensation, we would have them. It was beneficial as the information re: infection dates were in the files We also had an index box of 'live' people, and one for 'deceased/moved from the area' people. These were never moved from the unit and were locked away. Patients knew we kept a quick reference card index on them. It was particularly useful for Drs in the night or out of hours who could quickly access the card in the box which gave key information such as diagnosis, product used etc especially if the patients' medical notes were not on the unit. It is amazing how many patients visited the area and needed treatment out of hours in an emergency and that card was able to give key facts or came back to the area and we had something to help us find the medical notes. I don't know if other centres did that. The system was in place when I arrived and I do not know when or who started it but likely the centre doctor.

**Did the Centre, or any clinicians at the Centre, keep any separate records or files or information about patients who had been treated with factor concentrates and/or patients who had been infected with HIV, HBV and/or HCV?**

201. We had a whole separate file on people who had been treated with cryoprecipitate, with separate folders on their blood products usage. Also, files with look back studies. This was all on the actual digital medical files when this was brought in, but sometimes this information would be missed, so these files were invaluable and easy to access. However, they may not be there anymore. The files contained details of treatment used known as 'Oxford stats'. Batch numbers, when people had treatment, the amount and why. This information was eventually recorded on the Haem-track system I mentioned previously but had been kept on paper locally for our use when needed. This information enabled lookback studies for when there were recalls for products or concerns re: vCJD and product usage. Patients were also able to request what products they had and when for litigation purposes or to evidence exposure to infections that may have cleared.

**If you have had, at any time, any discussions or conversations or interactions with senior clinicians at the Centre about any of the matters set out in paragraphs 5 to 82 above, please provide (to the extent that you are able to) details of those discussions or conversations or interactions.**

202. I have said everything relevant above. We had weekly multi-disciplinary team meetings. between staff members, including doctors when we would discuss patients, issues and/or medical problems and bounce ideas around about how best to support the patients. It was also an opportunity for Dr Wide to teach us in depth about medicines, medical conditions and more about bleeding disorders or thrombophilia. We could also discuss ongoing litigation, look back studies and how we supported the patients when things such as vCJD came out, the UKHCDO stance on these things alongside the patient perspective.

## Statement of Truth

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

Signed _____Tracey Dunkley_____

Dated _____27 February 2023_____