Witness Name: Ms Emma Prescott

Statement No.: WITN6979001

Exhibits: WITN6979002, WITN6979003

Dated: 10 February 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MS EMMA PRESCOTT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 December 2021.

Section 1: Introduction

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

1.1. Name: Elizabeth Emma Prescott

Address: GRO-C

Date of Birth: GRO-C 1965

Professional qualifications: RGN, BSC (Hons) Oncology Nursing

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

2.1. 1988 – 1989: Staff Nurse – general surgical nursing – Singleton Hospital, Swansea

1989 – 1991: Staff Nurse – oncology nursing – Velindre Cancer Hospital, Cardiff

1991 – 1992: Course Nurse – Royal Marsden Hospital, London

1992 – 1995: Ward Manager – Haematology/Oncology – Whittington Hospital, London

1995 – present: Thalassaemia Nurse Specialist – Whittington Hospital, London

2006 – 2009: Hepatitis C Nurse Specialist – Whittington Hospital, (0.2 wte – in conjunction with 0.8 wte Thalassaemia role)

2.2. For point of clarity, all my answers are based on my experience from 1995 onwards (when I first took up post as Thalassaemia Nurse Specialist) and relate to transfusion-dependent β thalassaemia patients (see below). Prior to this I was not primarily involved in blood transfusion care.

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

3.1. Nil relevant

4. **Please confirm whether you have provided evidence to, or have been involved in, any other inquiries, investigations, criminal or civil litigation in relation to HIV, HBV and/or HCV in blood transfusions.**

4.1. No

Section 2: Whittington Hospital

5. Please describe:

a. **Your role and responsibilities at the Whittington Hospital ("Whittington Hospital") and how these changed over time.**

5.1. Historically, the Whittington Hospital thalassaemia patients were transfused on the paediatric ward. My role was designed to transition the patients, who were mostly adults at this time, over to a designated adult thalassaemia transfusion unit.

5.2. Background: β thalassaemia is a genetic disorder of haemoglobin production. It is inherited in an autosomal recessive pattern and is common in people originating from the Mediterranean, The Middle East, South Asia, South-East Asia and the 'Far East'. The disorder is due to a range of mutations associated with the β globin gene, resulting in reduced or absent production of β globin, one of the constituents of the adult haemoglobin molecule (HbA). Reduced β globin production, leading to excess free alpha (α) globin chains, damages red cell precursors in the bone marrow. This results in ineffective erythropoiesis, severe anaemia and compensatory erythroid marrow hyperplasia. In β thalassaemia major, haemoglobin production is so reduced that normal growth, development and quality of life can only be achieved by regular red cell transfusions from infancy. Death at an early age is inevitable if no transfusions are given. β thalassaemia intermedia refers to people in which a reduced amount of haemoglobin is produced, sufficient for growth and development without the absolute requirement for regular transfusions. Growth may fail and other complications may develop in later childhood and adulthood, requiring regular transfusions. However, there is a continuum or 'grey-scale' of clinical severity, with no absolute cut-off between the two.

The term 'non-transfusion dependent thalassaemia' (NTDT) is now commonly used to describe those who may require occasional, but not regular transfusion, in contrast to those whose haematology, symptoms and signs have required them to be treated with regular transfusions – 'transfusion-dependent thalassaemia' (TDT). *(Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK – 3rd edition, 2016)*

5.3. For clarity, the patients treated within the Whittington Hospital Thalassaemia Day Unit are transfusion dependent.

5.4. Initially, my responsibilities included blood transfusion management, pre-transfusion blood sampling, monitoring test results, vaccinations etc. As my experience developed my role incorporated iron chelation therapy* monitoring (efficacy and concordance issues), patient annual reviews (including arranging appropriate radiological investigations e.g. DEXA/MRI scans), appropriate referral to other relevant medical disciplines e.g. cardiology/endocrinology, liver biopsies for histology and iron quantification (now replaced with MRI/FibroScan® technology), participation in clinical research/clinical trials, nursing/medical education both nationally and internationally. Between 2006 and 2009 I was seconded for one day per week to the gastroenterology department to assist with the hospital's general Hepatitis C clinic.

5.5. *Iron overload secondary to blood transfusions is a common complication in transfusion-dependent β thalassaemia major and is usually fatal in the second or third decade of life if not treated. Iron chelation therapy refers to the treatment of iron overload.

b. Your work at Whittington Hospital insofar as it involves treating patients with blood transfusions.

5.6. The Whittington Hospital has over 140 adult patients with transfusion-dependent β thalassaemia. These patients require red blood cell (RBC) transfusions every two to four weeks (frequency usually depends on severity of phenotype/genotype). Patients receive between two to four leucocyte depleted RBC units during each transfusion episode (quantity of units usually depends on patient weight, haemoglobin level and existing co-morbidities such as heart failure etc.). The Whittington Thalassaemia Day unit is a nurse led unit. As Thalassaemia Nurse Specialist, I am responsible for the overall management of the transfusion unit.

c. **Your work insofar as it involved the care of patients who were infected with HIV, Hepatitis C ("HCV"), Hepatitis B ("HBV") viruses and/or other diseases patients may have been exposed to as a result of receiving a blood transfusion.**

5.7. In conjunction with the Royal Free Hospital's hepatology clinic and the Whittington Hospital's lead haematology consultant, I was actively involved in Hepatitis C anti-viral treatments (combination interferon-α2b/ribavirin, Pegylated interferon/ribavirin). My role was to teach patients how to safely administer interferon, monitor concordance to treatment, blood test monitoring, side-effect reviews, psychological support and follow-up reviews (in conjunction with the hepatology and haematology consultant).

6. **Please describe:**

a. **The roles, functions and responsibilities of the Thalassaemia Unit ("the Unit") within Whittington Hospital during the time you worked there.**

6.1. The role of the Whittington Thalassaemia Unit is to safely transfuse thalassaemia patients, to ensure appropriate and timely blood testing with

subsequent review and to be a direct access contact point for thalassaemia patients and their families.

b. Outline the facilities and staffing arrangements for the care of patients who needed to undergo or were undergoing blood transfusions.

6.2. The Whittington has a designated Thalassaemia Day Unit with dedicated nursing staff. The unit has seven recliner chairs and two beds. We currently treat patients between 09:00 and 17:00 Monday to Friday. The nursing team comprises of one band 8b (0.8 wte), one band 7 (1.0 wte), one band 5 (1.0 wte) and one band 3 Healthcare Assistant (1.0 wte). We are currently recruiting two full-time band 5 nurses and another full-time band 3 Healthcare Assistant. Medical assistance is provided by one Foundation doctor (Fy2) and two haematology specialist registrars. There is always an onsite haematology consultant during unit opening times.

c. Identify senior colleagues within the Unit and their roles and responsibilities during the time that you have worked there, insofar as they have been involved with the care of patients undergoing blood transfusions and/or patients infected with hepatitis and/or HIV in consequence of a blood transfusion.

6.3. Dr Beatrix Wonke (Consultant Haematologist – retired 2004 – was thalassaemia lead until retirement involved with both blood transfusion and Hepatitis C management)

6.4. Dr Bernard Davis (Consultant Haematologist – retired 2020 – involved with blood transfusion management)

6.5. Dr Farrukh Shah (Consultant Haematolgist – 2004 – present - involved with blood transfusion management)

6.6. Dr Emma Drasar (Consultant Haematologist – 2016 – present - involved with blood transfusion management)

6.7. Dr Annie McMillan (Consultant Haematologist – 2020 – present – Lead transfusion consultant)

6.8. Dr Ryan Mullally (Consultant Haematologist – 2021 – present - involved with blood transfusion management)

6.9. Mrs Niamh Malone-Cooke (Band 7 nurse – 2007 – present - involved with blood transfusion management)

6.10. Mr Abdul Adamu (Transfusion Practitioner) – 2005 – 2019

6.11. Mrs Jamilla Koshoni (Transfusion Practitioner – 2019 – present)

7. Please describe the practical steps that were taken when you decided that a patient required a blood transfusion, including:

a. How blood was requested from the hospital blood bank;

7.1. Whittington Hospital request form to be fully completed. Clinical details, date and time of requirements and number of units required to be stated. If this is a patient's first blood transfusion, then initial sample to be followed by a confirmatory sample (if no previous blood group record on Whittington Hospital's system). Cross-matched blood units are not released until second independent Group and Save has been performed. If the patient has been transfused elsewhere, phenotype/genotype if available, will be requested from their previous transfusion site. Only 'qualified practitioners' are authorised to take cross match sample. The

individual taking sample is responsible for labelling and signing the sample at the patient's side after positive identification.

b. What the record keeping requirements were

7.2. Patient written consent obtained and documented in patient case notes (please see below re: obtaining consent). Reason for transfusion, transfusion requirements i.e. frequency, volumes, duration of infusion etc. to be documented in case notes. Blood to be prescribed by qualified practitioner on blood transfusion prescription sheet. On collection of unit from blood bank, collection 'slip' to be completed with collector's name, signature and date and retained in blood bank ledger and copy to be completed and retained in external ledger within Day Unit. Following patient/blood unit 'cross-check', both copies of blood unit label to be signed with date and time. Sticker to be placed on blood transfusion prescription sheet. Detachable copy to be returned to blood bank to be scanned and placed on laboratory electronic system (maintained on system for 30 years). On completion of blood transfusion, consent form, transfusion prescription sheet, observation sheet and nursing evaluation sheet to be retained in case notes.

c. What the patient was told before the transfusion.

7.3. If patient's first blood transfusion, patient/guardian would be seen by consultant haematologist (with language interpreter if required). Patient would be made aware of risks and benefits of transfusion and given information leaflet. Risks explained would include infection, alloimmunisation, transfusion reactions, fluid overload, iron overload and transfusion associated cardiac overload. Written consent obtained.

8. Did you have, on behalf of the Unit, a relationship with the Regional Blood Transfusion Centre?

8.1. No

9. Did you have, on behalf of the Unit, a relationship with the National Blood Transfusion Service ("NBTS")? If so, please describe that relationship.

9.1. No

10. Approximately how many patients per week would receive a transfusion under the care of the Unit?

10.1. 50

11. Was any research undertaken within the Unit regarding blood transfusion patients?

a. If so, please explain what the research entailed, what the aims of the research were, whether patients were informed of their involvement in the research and whether consent was obtained.

11.1. The Whittington hospital's thalassaemia team have been involved in many studies relating to β thalassaemia patients. The majority of this research has revolved around iron overload (the most frequent complication associated with transfusion-dependent thalassaemia patients and the most likely cause of morbidity and mortality). Several studies were undertaken, in conjunction with The Royal Brompton Hospital, London, using T2* magnetic resonance imaging in the diagnosis and assessment of iron overload. Further studies have been undertaken looking at efficacy of iron chelation therapies. All patients were informed of their involvement and consent obtained.

b. Please provide details of any publications relating to the research

11.2. Please see appendix 1.

12. **Please list all research studies that you were involved with in any other relevant positions of employment (including any of the committees listed in your answer to question 3) insofar as relevant to the Inquiry's Terms of Reference, ensuring your answer addresses:**

12.1. N/A

Section 3: Policies and practices regarding blood transfusions

13. **To the best of your knowledge, was guidance provided to you and/or other medical professionals by Whittington Hospital as to transfusion policies and practices during the time of your employment? If so, please outline in as much detail as possible the policies in place which would prompt the need for a patient to receive a blood transfusion.**

13.1. Yes, hospital guideline/policy. Please see Appendix 2 (Whittington Health: Blood Policy – Prescription to Administration July 2020 – current policy) [WITN6979003]

14. **Page 4 of the April 2004 UK Thalassaemia Society newsletter [RLIT0000786] describes your attendance at the Leeds Thalassaemia Patient Support Group where you answered queries and provided information on transfusion protocol. Please explain:**
    a. **The nature of your involvement with the UK Thalassaemia Society and Thalassaemia Patient Support Groups;**

14.1. The UK Thalassaemia Society's (UKTS) is a national charity whose aim is to improve the lives of people living with thalassaemia. They provide invaluable support to patients across the UK. They not only support patients and their families, but also medical and educational professionals

involved in their care. They organise conferences for patients/families and healthcare professionals, to share information on latest treatments and support groups for patients. They have funded equipment and research and development. They also work with Public Health England and the NHS to promote screening and to develop national clinical standards. I have on many occasions given educational presentations at UKTS patient/healthcare professional conferences/workshops gratis.

b. **The information you provided on transfusion protocol to patient groups.**

14.2. My attendance at the above-mentioned support group meeting was not specifically related to transfusion protocols. It was a general question and answer session relating to many topics particularly iron overload and iron chelation therapy.

15. **Please outline the types of blood and blood products that were most commonly transfused to patients under your care, the circumstances in which they were used, and how this changed over time.**

15.1. Leucocyte depleted red blood cells only.

16. ***How, if at all, did policies for blood transfusion differ for paediatric patients? Please explain in as much detail as you are able to, and with respect to different types of blood transfusion.***

16.1. Unable to answer this question as not involved in paediatric care.

17. **Where applicable, were alternative treatments made available to patients with thalassaemia under the care of Whittington Hospital throughout the time of your employment? If so, please explain:**

17.1. N/A – β thalassaemia transfusion-dependent patients.

18. **With reference to any of the groups or committees outlined in question 3, please identify any significant policies relating to blood transfusion practice created by those groups in which you were involved, insofar as relevant to the Inquiry's Terms of Reference. Please describe the reason for and impact of the policy, and the extent of your involvement.**

18.1. N/A

19. **With reference to all of the committees named in your answer to question 3, please outline any specific transfusion policies created by those committees in relation to:**
    a. **Obstetrics;**
    b. **Trauma and emergency care;**
    c. **Surgery;**
    d. **Haematological cancer treatment;**
    e. **Thalassaemia;**
    f. **Sickle Cell Anaemia;**
    g. **Bleeding disorders (Haemophilia A, Haemophilia B, or von Willebrand's disease)**

19.1. N/A

20. **Was there a Hospital Transfusion Committee at the Whittington Hospital? If so:**
    a. ***Please provide a brief overview of the Committee, including when the Committee was created, its roles and responsibilities at Whittington Hospital, and its relationship with the Unit at Whittington Hospital.***
    b. ***With reference to any of the matters identified in question 18 of this request, please outline any significant policies or practices established by the Committee.***

c. ***Please explain the relationship between the Hospital Transfusion Committee and the Regional Transfusion Centre.***

20.1. The Transfusion Committee was initially created in 1998. Currently, this is a multidisciplinary committee which reports to the Trust Patient Safety Committee. The Transfusion Committee oversee, develop and implement the Trust's policies and procedures related to blood transfusion.

a) To advise and support the Transfusion Team

b) To escalate issues of concern relating to blood transfusion to the Operational Governance Committee, the Director of Operations and Chief Executive as appropriate and advise on any remedial action.

c) To produce a quarterly report on the compliance of the Trust with relevant regulations and recommendations for the Operational Governance Committee.

d) To review and recommend transfusion policies for approval by the Executive Committee. To approve underlying transfusion procedures and guidelines.

e) To review the performance of the Trust in the following areas and to agree any recommendations for change and service improvement:

- **i.** Serious transfusion adverse events or reactions reported to Medicines and Healthcare products Regulatory Agency (MHRA) and Serious Hazards of transfusion (SHOT) scheme
- **ii.** National and Regional audits of clinical transfusion practice
- **iii.** Blood usage and wastage, including comparison with peers
- **iv.** Laboratory performance, including turnaround, external quality assessment and compliance with the United Kingdom Accreditation Service (UKAS)
- **v.** Compliance with MHRA, Care Quality Commission (CQC)
- **vi.** Compliance with National Guidelines
- **vii.** Compliance with Health Service Circular (HSC 2007/001)

f) To agree an on-going programme of local audit of clinical transfusion practice

g) To Make recommendations on the structure and content of local training programmes

h) To advise on the implementation of new national recommendations and regulations

i) To make any other recommendations for change in practice in the interest of improved patient care

Transfusion thresholds and frequency

21. ***Please outline:***

a. **At which level generally a patient with thalassaemia's haemoglobin count would be considered low and thus require a blood transfusion, and how this level may have changed over time.**

21.1. To reduce ineffective erythropoiesis, extramedullary hematopoeisis, hypersplenism/splenomegaly and reduce bony complications including osteoporosis/fractures, pre-transfusion haemoglobin levels should not drop below 95g/l. Well chelated patients (low body iron levels) can be optimally transfused with pre-transfusion haemoglobin levels of 100g/l thereby significantly reducing morbidities associated with chronic anaemia.

b. **How patients' haemoglobin levels were monitored before, during and after a transfusion**

21.2. Patient's haemoglobin levels are checked two to three days before scheduled blood transfusion to determine transfusion date and again on the day of transfusion to determine the number of RBC units to be administered. Post transfusion haemoglobin levels are not routinely checked as these patients tend to have very poor venous access (due to repeated phlebotomy). To bear in mind that these patients are mostly young and healthy with no cardiac/renal complications. If a patient was

cardiac compromised an individual care plan would be designed for this patient.

c. **The general frequency of transfusions for patients with thalassaemia and how this may have changed over time.**

21.3. The frequency of transfusions depends on factors including thalassaemia genotype (severity of disease) and whether the patient has previously undergone splenectomy (thereby reducing red cell requirements). Each individual patient is assessed on an on-going basis regarding transfusion frequency. Generally, the transfusion dependent thalassaemia patients require transfusions between two to four weeks.

22. **Were any audits or surveillance programmes regarding the use of blood transfusions by the Unit conducted at Whittington Hospital? If so, please explain these processes and the impact they had on blood transfusion standards and practice.**

22.1. No

23. **With reference to your experience at Whittington Hospital and in any other relevant roles, please outline if you believe that blood transfusions were provided unnecessarily or excessively for patients with thalassaemia. If so, please explain in as much detail as you are able to recall, including why this may have occurred and how, if at all, this changed over time.**

23.1. No

Blood and blood components

24. **Were you aware, at any time, of patients being given transfusions of red blood cells from the USA? If so, was there any concern about its safety at the time?**

24.1. No

25. ***The enclosed UK Thalassaemia Society newsletter, dated September 1987, [RLIT0000783] contains a plea to patients with thalassaemia to ensure the blood they received was filtered as it had come to the attention of the Society that some hospitals were not giving filtered blood because it was too expensive.***

a. **Please explain what was meant by filtered blood;**

25.1. Leucocyte removal filters are used to reduce complications/reactions associated with transfused white blood cells that are contained in units of red blood cells. Filters may be used at the bedside, in a hospital blood bank, or in a blood collection centre.

b. **Please explain the perceived benefits and/or risks associated with transfusing patients with thalassaemia with filtered blood and specifically, those benefits and/or risks in comparison with unfiltered blood;**

25.2. To significantly reduce non-haemolytic febrile transfusion reactions caused by cytokines from leucocytes in transfused red cells.

c. **Was filtered blood transfused to patients with thalassaemia under your care? If so, please outline the circumstances in which filtered blood would be administered and the circumstances in which filtered blood would not be administered.**

25.3. In my own experience from 1995 onwards leucocyte filtered blood was and is transfused to all thalassaemia patients.

Section 4: Knowledge of risk

General

26. Please outline the ways in which nurses working with patients with thalassaemia sought to keep themselves, or were kept, updated on any risks associated with treatment, specifically those associated with blood transfusions.

26.1. Hospital Infection Control Team advice. All nurses are now required to undertake two e-learning blood transfusion education modules (Learnpro Modules) biannually to update on amongst other things, safety issues:

a) Safe Transfusion Practice
b) Blood Components and Indications for use

27. When you began working with patients with thalassaemia, what did you know and understand about the risks of infection associated with blood transfusions? What were the sources of your knowledge? How did your knowledge and understanding develop over time?

27.1. I was aware of Hepatitis B, Hepatitis C and HIV as transmissible viruses through information from hospital Infection Control Team, medical/nursing literature and other public media sources.

28. In your experience at Whittington Hospital, did any particular blood products or transfusion methods carry a higher risk of viral infection?

28.1. My experience is only with red blood cell transfusions

29. What was your knowledge and understanding of the risks and transmission of hepatitis, including HBV and HCV from blood transfusion? What were the sources of your knowledge? How did that knowledge and understanding

29.1. My understanding was that these were blood-borne viruses transmitted through blood and other body fluids containing the virus. The rate of viral transmission varies depending on the route of transmission, the type of virus, viral load and the immune status of the exposed person. The more common routes of transmission include transfusion of blood products, sexual intercourse, sharing injecting equipment/needlestick injury, skin puncture by contaminated sharp objects e.g. tattoos and childbirth. Sources of knowledge include Infection Control Team advice and guidance, medical/nursing publications, media.

HIV and AIDS

30. When you began work as a nurse, what was your knowledge and understanding of HIV and AIDS and in particular of the risks of transmission through blood transfusions? How did that knowledge and understanding develop over time?

30.1. Same as above

Other

31. If you were responsible for making decisions and actions on behalf of the Unit in response to any known or suspected risks of infection, please explain what decisions were involved. If applicable, do you consider that those decisions were adequate and appropriate? If so, why? If not, please explain what you believe could or should have been done differently.

31.1. Decisions involved appropriate infection control training for all staff. Training included safe blood sample collection e.g. appropriate blood

collection equipment (not traditional syringe/needle), safe handling/disposal of sharps, appropriate protection gears such as gloves, safe and appropriate cleaning/disposal of contaminated equipment.

32. At the Unit, was there any monitoring of the incidence of transfusion-transmitted infections in patients? If so, please explain these processes, the findings, and the impact they had on blood transfusion standards and practice.

32.1. All new patients (previously transfused elsewhere) were counselled and tested for Hepatitis C antibody (if positive then tested for HCV RNA), Hepatitis B sAg and HIV antibody. All thalassaemia patients attending the unit were/are tested annually as above. All transfused patients are immunised against Hepatitis B and their antibody titres measured yearly. Booster vaccinations are given when required. From my appointment in 1995 we have had no new incidences of infection in our patient cohort.

33. Did Whittington Hospital have any procedures in place to ensure patients reported any adverse reactions or symptoms? If so please explain:

a. What procedure did the Hospital have in place?

b. Did this procedure extend to after a patient had been discharged from Hospital

c. Were patients asked to report any adverse reactions or symptoms within a certain timeframe?

33.1. All patients were/are advised to contact the Day unit (if within 'working' hours) or the on-call haematology doctor (if 'non-working' hours) to report any adverse transfusion reactions or symptoms as soon as possible. This extends to after the patient has been discharged. Patients were/are advised to urgently seek medical attention from the hospital Accident and Emergency Department if reaction deemed severe or life-threatening.

d. **If clinicians were informed and/or became aware of a patient having suffered any adverse reactions or symptoms, who were they required to report this to?**

33.2. Serious Hazards of Transfusion (SHOT)

e. **Was there any mechanism for the Hospital to report any adverse reactions or symptoms to the Regional Transfusion Centre?**

33.3. Yes. Samples would/are sent off to Red Cell Immunohaematology (Colindale, NHSBT) for full investigation.

f. ***In the event of a patient's death after receiving a blood transfusion, what process was followed? Specifically, in relation to the registration of the death and/or any consideration of what was recorded on the death certificate.***

33.4. No deaths

Section 5: Treatment of patients

Provision of information to patients

34. **Were you involved in discussions with patients or their relatives regarding risks of infection by blood transfusion? If so, what information did you provide or cause to be provided to patients under your care at the Unit about those risks prior to treatment commencing?**

34.1. No. The haematology consultant would discuss risk of infection through blood with all patients.

35. If the nature of provision of information changed over time during your employment, please explain what changes occurred and the reasons for any such change/s.

35.1. Patient information leaflet initiated at some point to enhance information that patients were given by haematology consultant.

36. Did the Unit have a process of informing patients that they had received, or might have received, infected blood through a transfusion? If so, how were patients and/or their relatives informed? What, if any, involvement did you have in this process?

36.1. Not able to answer as no patients received or were thought to have received infected blood through transfusion during my employment.

Consent

37. Are you aware if patients under the care of the Unit were treated with blood transfusions without their express or informed consent? If so, how and why did this occur?

37.1. No

HIV

38. To the best of your knowledge, were any patients under your care or the Units' care infected with HIV as a consequence of a blood transfusion? If so, how many?

38.1. No patients infected with HIV

Hepatitis C

39. Are you aware if the Unit tested patients for HCV? If so, please describe the process at the Unit for HCV testing, including pre-test and post-test counselling. What was your involvement in this process?

39.1. Every transfusion-dependent thalassaemia patient was/is tested annually for Hepatitis C antibody. If antibody positive a further sample was/is sent for quantitative HCV RNA. I was/am involved in both pre-test and post-test counselling. Information was/is always provided in a clear and concise way that the patient can understand. The following areas were/are covered: confidentiality of test results, modes of transmission, the nature of hepatitis C infection and possible long-term implications, implications of a positive result for the patient, the testing procedure, how long before the results come back, what the results will mean and possible need for specialist referral and treatment options. Informed consent.

40. To the best of your knowledge, were any patients under your care or the Units' care infected with HCV as a consequence of a blood transfusion? If so, how many?

40.1. During my employment from 1995 no patients treated at the Whittington Thalassaemia Unit have been infected with HCV as a consequence of blood transfusion. Prior to 1991 there were nine Whittington thalassaemia patients in total who were found to be HCV RNA positive (most likely mode of infection through contaminated blood). Six other HCV RNA positive thalassaemia patients were referred to us from other UK centres (most likely mode of infection through contaminated blood), and five HCV RNA positive patients transferred to us from centres outside of the UK (most likely mode of infection through contaminated blood).

41. For patients who had contracted viral infections through blood transfusion or any other means, how did their infective status affect your practices and the treatment you were able to provide?

41.1. Treatment remained the same for the infected patients as the non-infected patients. Their infective status had no impact on our practices or the treatment that they required.

Treatment for HIV and/or Hepatitis as a result of receiving an infected blood transfusion

42. How was the care and treatment of patients with thalassaemia who also had HIV managed within the Unit?

42.1. N/A – no HIV infected patients

43. How was the care and treatment of patients with thalassaemia who also had HCV managed within the Unit? In particular:

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

43.1. All patients found to be HCV RNA positive were referred to the Hepatology Clinic at the Royal Free Hospital, London. Their thalassaemia management remained at Whittington Hospital.

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

43.2. Anti-viral treatments were directed by the hepatology team. Monitoring before, during and after treatment/s were carried out at the Whittington Hospital with three monthly tertiary reviews with hepatology. Surveillance monitoring included liver biopsies for histology/grading (now replaced with FibroScan®), MRI assessment of liver iron loading, endoscopy for detection of varices, viral load measurements and liver function tests. All patients (still living) are now HCV RNA negative but any who were found to have sustained a

degree of liver damage continue to be monitored by the hepatology team.

44. How was the care and treatment of patients with thalassaemia who also had HBV managed within the Unit? In particular:

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

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

44.1. No patients were infected with HBV

45. When and in what circumstances did you become aware of the risks of transmission of vCJD associated with the use of blood transfusions? Please explain how your knowledge developed over time.

45.1. Media coverage in and around 2003. Subsequent medical publications

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

46.1. No

47. What measures were put in place from a public health perspective at Whittington Hospital in relation to the care and treatment of patients in light of the risk associated with vCJD transmission by blood transfusion?

47.1. All RBCs leucocyte depleted – To note, all β thalassaemia patients had already been receiving leucocyte depleted blood for many years prior to this. In conjunction with NHSBT Colindale, automated red cell collection was initiated so that two units of red cells could be collected during a single

donation procedure from individuals who had a high enough red cell mass. The use of double dose red cell product for transfusion to a single patient confers benefit in terms of reduction in donor exposure. For further information please contact NHSBT Colindale.

48. **With reference to all of the committees named in your answer to question 3, please outline the extent to which any of those committees were involved in assessing and managing the risk of vCJD transmission by blood transfusion.**

48.1. N/A

Section 7: Other Issues

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

49.1. None

50. **Please provide any further comment that you wish to provide about matters of relevance to the Inquiry's Terms of Reference.**

50.1. None

Statement of Truth

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

Signed GRO-C

Dated 10.02.2022..