Witness Name: Ishbel McDougall
Statement No.: WITN0920001
Exhibits: WITN0920002
Dated: 12 November 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ISHBEL MCDOUGALL

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

I, Ishbel McDougall, will say as follows: -

Section 1: Introduction

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

   My name is Miss Ishbel McDougall.
   My address is % Central Legal Office, Edinburgh.
   My Date of Birth is GRO:C 1957.

2. **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.**

   Employment History:

   - Student nurse, Greater Glasgow Health Board and Eastern College of Nursing and Midwifery (11th August, 1975 until 28th September, 1978, General nurse training). Qualified September 1978.

- Staff nurse in Acute Medical Admissions Unit Glasgow Royal Infirmary, Scotland (1978 until 1980). Assisting in care of acutely ill patients admitted with medical conditions, stabilising condition before transfer to general medical wards.

- Student midwife, Perth Royal Infirmary, Scotland (May 1980 until May 1981). Qualified May 1981.

- Staff Nurse/Sister in Acute Medical Admissions Unit. Glasgow Royal Infirmary, Scotland (June 1981 until September 1985). Care of acutely ill patients with medical conditions until transfer to general medical wards.

- Agency nurse with British Nursing Association (December 1985 until May 1986).

    1. Ravenspark Hospital, Irvine. General nursing care of psychogeriatric patients.
    2. General nursing care of an elderly gentleman in his own home.

- Nursing Sister, Haemophilia Unit, Glasgow Royal Infirmary, Glasgow. June 1986 until retiral at end of May 2018.

<u>Responsibilities in the Haemophilia Unit.</u>

Assess, plan, implement and evaluate treatments along with other members of the team. Recognise changes in the patient's condition/ bleeding episodes, reporting to medical staff and take appropriate action. Refer patients as appropriate to other members of a multidisciplinary team. Ensure continuity of care. Help patients and their families adjust to changes in their condition and help enable them to make informed decisions about their care.

Support patients and their families when a diagnosis is made and give them the information they require to deal with it on a day to day basis. Help patients obtain the best treatment, taking into account those with special communication and learning

needs. Help patients gain full monetary benefits. With the patient's consent, advise an employer on the provision of facilities where the patient can give himself treatment in a safe environment within his workplace if required.

Liaise with employers, places of education, voluntary organisations and statutory authorities to represent the interests of people with haemophilia. Give advice on the special needs of patients with haemophilia to a wide range of healthcare professionals including doctors, nurses, dentists and carers. Responsible for maintaining own professional education and development. Provision of education for health care workers involved in caring for people with haemophilia in a hospital or community setting. Making current information available to patients. Teaching patients and their families the practical, theoretical aspects and complications of home therapy, including the preparation and administration of treatments. Ensure patients and carers have sufficient knowledge where and when to access advice. Be aware of research in clinical practice and participate in data collection, clinical studies and trials along with other members of the team.

3. **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.infectedbloodinguiry.orq.uk), including the dates of your membership and the nature of your involvement.**

   Throughout my employment in the Haemophilia Unit of the Glasgow Royal Infirmary I supported the Haemophilia Society and Haemophilia Scotland. During my nursing career I have been a member of the Royal College of Nursing.

4. **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.**

I provided a written statement to the Penrose Inquiry, but was not asked to give oral evidence. I have not been involved in any other inquiries, investigations or litigation. A copy of the statement I provided to the Penrose Inquiry is attached.

The statement was made under very stressful conditions as I was unable to read through the questions beforehand or organise my thoughts and answers in any way. I feel that the statement I am submitting to the Infected Blood Inquiry is much superior, giving a clearer and more in depth picture of events as I remember them during the years in question.

Section 2: The Haemophilia Centre at Glasgow Royal Infirmary ("the Centre")

5. 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.

I was employed as the Sister in the Haemophilia Unit from 6th June 1986 until 31st May 2018 when I retired. I worked alongside, and under, the supervision of Dr Charles Forbes (Co-Director) until August 1987 when he moved to Dundee and was succeeded as Co-Director by Dr Gordon Lowe, who was joined by Dr Isobel Walker as Co-Director from 1990, and then by Dr Campbell Tait from 1999.

My responsibilities were as previously outlined and amongst other things included;

- Dealing with phone enquiries, referring on as necessary to other members of the team.
- Treating outpatients and inpatients and helping to arrange any further treatment or follow up required.
- Education of ward staff.
- Preparing and assisting at clinics.
- Assisting the medical staff in the education of patients on inheritance, diagnosis, treatment of bleeding episodes, transmission of viruses and safe use and disposal of sharps, how to deal with open wounds and mopping up of spillages.
- Continuing to record factor/product usage for annual UKHCDO returns to Rosemary Spooner in Oxford.

- Recording of bleeding episodes and their treatment.
- Liaising with other members of the multi disciplinary team.
- Making home visits along with social worker, Mrs Miriam Guthrie, to support patients and their families.

6. **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.**

Dr John Davidson, Consultant Haematologist in charge of Blood Transfusion and Blood Products Laboratory in Royal Infirmary Glasgow, was responsible for ordering blood products from the PFC in Edinburgh or occasionally from commercial manufacturers of factor concentrates.

Dr George McDonald, Consultant Haematologist and Head of Department of Haematology, was Co-Director of the Unit with Dr Forbes. Dr Charles Forbes Co-director - was in control of policy development and practice in the Unit. Drs George McDonald and Charles Forbes shared the responsibility for the Haemophilia Unit.

Dr Gordon Lowe, Consultant Physician, assisted Dr Forbes with the day to day management and running of the Unit and care of patients in the general medical ward. Drs Forbes and Lowe were the driving force of the Unit.

The medical staff were responsible for the decisions as to allocation of products, use of products to treat bleeding episodes and for providing patients with information regarding diagnosis, testing, treatment and results. As the nursing sister I would go over again the information given by them and answer any questions the patients may have had.

Dr Keith Spowart, Medical/Haemophilia SHO based in Wards 2 and 3, assisted in the daily running of the Unit and treatment of patients under the guidance of the

Consultants. Dr Spowart would be succeeded by Dr Lin Soo from 1988, Dr Elizabeth Kirke Clinical Assistant from 1992 and finally Dr Arif Alvi Associate Specialist from 2000.

Dr Rajan Madhok, Consultant Rheumatologist, assisted with the treatment and rehabilitation of patients following joint bleeds.

Mrs Miriam Guthrie, Senior Social Worker, carried out general social work duties, assistance with benefits, housing issues and supporting/counselling patients who had been infected with HIV or hepatitis and their families.

Mrs Patricia Wilkie Counsellor - assisted Dr Forbes from 1985 with counselling patients before and after diagnosis of HIV. Mrs Guthrie took over this role when Mrs Wilkie left in December 1987.

Physiotherapy input was provided by Fiona McChesney who was succeeded by Fiona (surname unknown) who was succeeded by Lorraine Friel. Dates unknown but each staff member worked with the haemophilia patients for a number of years.
All of the physiotherapists had other duties, for example, general physiotherapy patients, hydrotherapy patients or rheumatology patients to treat as well as their haemophilia workload.
Their haemophilia role was;

- to assist with the patient's rehabilitation following musculoskeletal bleeds.
- to maintain mobility and function of joints.
- help prepare the patient for orthopaedic surgery and with post operative rehabilitation.
- develop treatment plans.
- give advice on managing long-term conditions.

The staff in the Unit worked together well as a team to ensure the best possible practice, support and treatment for the patients.

Section 3: Knowledge of risk

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

The Unit's approach, and the approach of the senior clinicians, has always been, I believe, to provide the patients with a high standard of care. This involved keeping the patients advised of any developments and problems related to treatment with blood products and balancing the risks of treatment against the potential outcome of not treating bleeding episodes i.e. crippling arthritis or even death. The Unit's pursuit of best practice can be seen in the evolution of treatment and its use:

- Reduction in amount of factor concentrates used because of known risk of hepatitis e.g. the use of desmopressin, cryoprecipitate or plasma.
- Introduction of heat treated products to prevent transmission of HIV and HCV from 1985.
- Introduction of recombinant factor VIII and factor IX from 1997.

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

The Unit's medical staff were aware of the benefits of home treatment. Severely affected patients had been commenced on home therapy at the GRI or more often at the RHSC (Royal Hospital for Sick Children) prior to being transferred to the Adult Centre in the GRI (Glasgow Royal Infirmary). However, on transfer from the RHSC we would go over the benefits of home treatment, dosages and safe use of and disposal of sharps with the young men.

Advice given and benefits were/are:

- Treat early signs of a bleed to prevent damage later on.
- Early treatment also reduced the amount of blood products used thus reducing risk of virus transmission.
- Reduction of time off work and time spent attending the hospital for treatment.
- Reduction of cost attending the hospital for treatment.

- Increased freedom and improved quality of life.

The Unit's approach to home treatment has been consistent over the years with the long term benefits being seen in the adolescents who transfer from the RHSC having few, if any, target joints or haemophilic arthritis. A target joint is a joint that has had recurrent bleeding episodes. It is a common complication of severe haemophilia.

With the introduction of heat treatment, virus inactivation, and in the 1990s of recombinant factor VIII and IX, the risk of virus transmission, in particular hepatitis and HIV, has been eliminated.

The increased availability and safety of factor concentrates allowed the Unit staff to encourage the patients to treat prophylactically to, not only, reduce the incidence and severity of bleeding episodes but also to encourage the patients to take part in sports, holiday abroad and lead a more normal life. The Unit to this day encourages the use of prophylaxis.

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

As I worked in the Adult Centre and did not deal with the care of children on a day to day basis I feel it would not be my place to discuss the approach taken for the treatment of children at the RHSC.

10. **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.**

The Unit followed guidelines developed by the UKHCDO. The UKHCDO is a group of haemophilia doctors who manage patients with bleeding disorders. It was set up to improve haemophilia care. These guidelines may be viewed on the UKHCDO website.

Drs Lowe and McDonald were involved with the preparation of the first treatment guideline issued in May 1988. The Unit staff followed this guideline.

It was the policy of Dr Forbes, and the Unit medical staff, to use plasma or cryoprecipitate for mildly affected patients if desmopressin or tranexamic acid were ineffective thus reducing the risk of virus transmission.

The Haematology Department minimised exposure to the number of donors of factor concentrate through a batch dedication system.

The Scottish and Northern Ireland Centre Directors developed a guideline relating to the transfer of patients from blood products to recombinant Factor VIII. (See annexe 8 of the Penrose Inquiry).

Drs John Morris and Ewan Forrest (his colleague) wrote a local guideline for the testing, treatment and follow up of haemophilia patients infected with HCV.

There was an unwritten standard operating procedure that all patients would have Hepatitis B and liver function tests carried out routinely at clinic reviews to monitor for inflammation of the liver due to Hepatitis B or non A-non B (NANB) Hepatitis and/or look for signs of new infection. Hepatitis C testing started in 1991 and Hepatitis A in 1992.

The guidelines would be updated in later years to reflect the treatments available at the time.

11. **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?**

Having come from a background of acute medical admissions I had often nursed patients requiring transfusion of blood and/or blood products and so had a knowledge

of good transfusion practice and potential complications. I was aware of the risk of allergic reaction, hepatitis and antibody formation. Learning about treatments and their complications often took the form of reading articles in nursing and medical journals, discussions with other members of nursing staff and, of course, learning from the medical staff on ward rounds.

When I took up post in the Haemophilia Unit many of the patients had already demonstrated elevation of liver enzymes indicating inflammation of the liver. This was described as NANB Hepatitis. Both the previous Haemophilia Sister and the medical staff discussed these findings with me including causes, management and steps taken to reduce the transmission risk.

12. **What was your understanding as to the risks of the transmission of hepatitis (including Hepatitis B and Non A Non 8 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?**

Having never used commercially produced blood products prior to working in the Haemophilia Unit I was not aware of the risk involved in their use until I was informed of it as part of my introduction to haemophilia, its treatment and related complications by Sister Campbell, Dr Forbes and Dr Lowe.

By the time I started working in the Unit the SNBTS had introduced heat treatment of their factor concentrates and commercial companies had already included new procedures to screen donors, to virally inactivate their products and test their products at various points during its manufacture to ensure its safety. In later years we were informed on a regular basis, by representatives from the commercial companies whose products we continued to use, on the safety of their products.

13. **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?**

The more I learnt about the way blood products were manufactured and how blood donations had been sourced the more I understood how viruses were able to enter into the treatments. As I learned about the history of haemophilia and how repeated bleeding episodes affected muscles and joints causing deformities, pain and arthritis or even death the more I understood why haemophilia doctors continued to use blood products although they knew that they could cause hepatitis. They balanced the risk of treatment based on the little knowledge they had at that time of the chronic effects of hepatitis against the long term effects of bleeds.

Knowing that the viruses could be spread through blood to blood contact, needlestick injury and sexual intercourse I was aware that an important part of my job was to help prevent others being infected. This was done through education of patients, their partners and colleagues and by example. Procedures were already in place to reduce the transmission risk as outlined below and it was my responsibility to continue the good work of my predecessor and my medical colleagues.

At the start of my career in haemophilia in 1986 I knew very little about HIV. There was a lot to learn and this was done by asking the medical staff questions, reading articles in journals, and of course, speaking to the patients. As my knowledge increased and my understanding of both the physical and emotional effects grew I feel I was better able to give the patients support. I was increasingly able to identify problems related to the disease such as skin lesions, respiratory problems and oral thrush and would pass on my concerns to the medical staff for further examination and treatment. My knowledge base was expanding and included infection control policies, care of the terminally ill, treatments available for HIV and their side effects amongst other things. I felt better able to support the patients and my work colleagues.

14. 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?

Blood and plasma were known to transmit viral hepatitis since the practice of blood transfusion began in the 1940s. Patients with haemophilia required repeated transfusion of blood products and therefore were at increased risk. When I took up post as Haemophilia Sister in 1986 the products being used had already either been heat treated or gone through some other viral inactivation process during manufacture. I was never in a position where I had to assess the potential risk of one product against another.

15. 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?

The medical staff put procedures in place to reduce the risk.

- The blood transfusion service introduced screening of donors for hepatitis B.
- Episodes of hepatitis following transfusion of blood products were identified by screening for hepatitis B and NANB hepatitis and then reported to the blood transfusion service for investigation of the donor.
- Patients and staff were informed of the risks and how to reduce transmission by blood to blood contact; covering open wounds, use of condoms, safe use and disposal of sharps, dealing with blood spillages etc.
- Specimens of blood and other body fluids were identified with a "Dangerous Specimen" label prior to being sent to the laboratories.
- Measures to prevent cross infection had been introduced including; use of disposable gloves and aprons, safe use of and disposal of sharps, how to mop up spillages and ensuring staff and patients knew how to deal with a needlestick injury.
- Communication with other clinical staff to advise of risk.
- Hepatitis B vaccination for both staff and patients was introduced in 1985 with monitoring of immunity and booster vaccines as required. Carers of infected patients were advised to seek vaccination from their GPs. Hepatitis A vaccination was introduced later in 1992 after reports of hepatitis A transmission from a non-UK commercial product. Vaccinations against hepatitis A and B continue to this day by the Unit or GPs for those patients requiring blood products.
- Liver function tests were performed routinely at clinic visits and exposure

to NANB hepatitis documented in notes and discussed with patients.

Any information/advice in relation to advising the patients of the risks of infection associated with the use of blood and blood products would have come from my work colleagues and by understanding why the above procedures were in place. As mentioned previously when I took up post the products we used had already been virally inactivated.

16. 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.

Medical staff sought to reduce the amount of blood products used to treat bleeding episodes to reduce the risk of transmission of viruses.

Epsilon-aminocaproic acid, followed by tranexamic acid, were introduced and later on desmopressin. If the former were ineffective the use of plasma or cryoprecipitate, in a bid to reduce the amount of blood products, was used. Batch dedication reduced exposure to recipients of factor concentrates.

Severely affected haemophiliacs were commenced on home treatment which improved their quality of life and reduced, in the long term, the amount of concentrates used.

Dental extractions were limited to two teeth at any one time to reduce factor concentrate requirement and length of admission. Patients were advised on dental hygiene and encouraged to have regular dental check-ups to avoid the need for extractions.

Mr Reid was the dental surgeon who looked after the haemophilia patients when I started working in the Unit. He was followed by Mr Andrew Brewer and he was later joined by Mrs Tara Dunseith. Mr Brewer did the surgical procedures and Mrs Dunseith the restorative work.

Factor VIII and Factor IX concentrates were introduced in the 1970s and by 1983 Scotland was almost self-sufficient. Concentrates were made from pooling many donations and therefore the risk of transmission of viruses would be elevated.

Heat treatment of concentrates was introduced in 1985 to prevent the transmission of HIV. In 1986 a more intensive heat treatment (higher temperature for a longer period of time) was introduced to prevent transmission of viral hepatitis.

Regular monitoring of blood liver function tests continued.

By 1993 Scottish and Northern Ireland Haemophilia Centre Directors had completed a study of the SNBTS Factor VIII concentrate which showed that no previously untreated patients had developed abnormal liver function tests nor antibodies to hepatitis C virus. Patients and staff were reassured of the safety of this product.
Please refer also to the answer to Q15.

Section 4: Testing, treatment and care of patients

17. 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?

Both the medical and nursing staff were involved in discussions with patients regarding the risks of haemophilia and its treatment, including inhibitor formation, allergic reaction and hepatitis.

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

In January and April 1985 Dr Forbes sent letters to patients registered in the GRI haemophilia unit who had been treated with blood products informing them that cases of AIDS and HIV had been identified in the haemophilia population and advising them that all patients treated with blood products should take care with

blood, sharps and sex to reduce the risk of transmission. At review appointments the risks would be discussed and once a reliable test had been developed, testing would be carried out with the patient's consent. The second letter sent out in April included a Haemophilia Society booklet called "AIDS and the Blood".
Once testing became available the patients were seen by Dr Forbes and Mrs Patricia Wilkie, an experienced counsellor, and pre and post test counselling was carried out. Dr Forbes with Mrs Wilkie informed the patients of their results.

Most of this work was done by the time I took up post in June 1986 and part of my job was to go over the advice/information with the patients that had been given previously by my colleagues. Leaflets were also available from the Haemophilia Society on haemophilia and the risks of treatment. For patients on home treatment the data sheet with the factor also provided information and mentioned the risk of hepatitis. I understand that examples of these were provided to the Penrose Inquiry

Patients were informed by medical staff that the only alternative to blood products was desmopressin and that desmopressin was limited in its use to mild haemophilia A and mild von Willebrand's disease.

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

Both the doctors and nurses were involved in the initiation of home treatment therapy. Most severely affected patients had already commenced on home treatment at the RHSC. Nursing staff dealt with the more practical aspects whilst medical staff would discuss dosages and timing etc.
Topics discussed would include:

- The risks - allergic reaction, inhibitor development, transmission of viruses.
- Factor requirements for types and severity of bleeds.
- Reconstitution of factors.
- Venepuncture and safe infusion practice.
- Safe disposal of sharps.
- Dealing with needlestick injury.

- Documentation of bleeds and usage.
- Who and when to contact for advice.
- Importance of regular attendance at review clinics.

20. **What was the Centre's approach and the approach of senior clinicians at the Centre 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?**

At the time of testing for HIV and HCV I don't think there was a specific written guideline in relation to asking for consent. If a patient was advised which blood tests were to be taken at clinic visits (known as routine samples) and gave permission for venepuncture this was taken as "verbal consent". The medical staff normally saw patients first at review clinics and then the nurses would take the requested blood samples. Patients were able to ask nurses which blood samples were being taken if they were unsure.

Again if a patient required treatment for a bleed or prophylaxis and the need for treatment explained and accepted this was taken as consent - verbal consent.

Over time the staff became more aware of the issues of consent and documentation of discussions with patients and we attended Good Clinical Practice training on a regular basis. Patients became increasingly aware of their rights and were more confident in making decisions for themselves based on the information they had been supplied with. I think this probably developed gradually and for a number of reasons. In society we were being encouraged to take some responsibility for our health and wellbeing by maintaining a healthy weight, eating a good and balanced diet and reducing stress in our lives. The internet provided a wealth of both good and bad information which could be accessed easily. People wanted more involvement in their care and became more at ease asking questions.

21. **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.**

I don't remember any specific training for consent to treatment or testing in the 1980s - 1990s. However, as part of my nurse training we were encouraged to communicate with patients in a way that they understood, to allow them to ask questions and to know our subject when discussing treatment plans. If they agreed to the plan that was taken as consent.

Verbal consent and pre and post counselling were always carried out by the medical staff for an HIV test.

Good Clinical Practice training days which we attended regularly included discussions around consent.

22. 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?

All of our patients had been informed of their HIV diagnosis. I was never told to withhold information from a patient.

23. 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?

We routinely took blood samples from patients at their clinic appointments. The medical staff saw the patients at the clinic first and would say to the patient that they would like to take some routine blood samples. The patient would then come to the nursing staff for those samples to be taken. Both the doctors and nurses would explain to the patient the importance of the routine blood samples to look for signs of anaemia, inflammation of the liver, kidney disease and inhibitor formation.

Blood samples were taken for the following tests;

- Full blood count to check for signs of anaemia.
- Kidney function as haemophilia patients are prone to haematuria and kidney disease.

- Liver function tests to look for the presence of hepatitis.
- Clotting factor level.
- Factor VIII / IX inhibitor screen.
- Hepatitis B carriage and immunity, followed by Hepatitis C antibody and antigen and Hepatitis A immunity from 1992 onwards.

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

Both the medical and nursing staff would discuss the need for these blood tests with the patients and why they were important as part of routine surveillance to identify problems and initiate investigations and/or treatment as required.

The medical staff discussed previous blood test trends during the review appointment. Patients were aware that they would be contacted by phone or letter if test results were abnormal and had to be rechecked at another appointment. Medical staff discussed results with patients.

25. 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?

In 1985 discussions took place with patients prior to HIV testing. This was done by Mrs Patricia Wilkie, Dr Charles Forbes, Dr Lowe and other medical staff. Patient consent and pre and post counselling were always required for an HIV test. This was done by the medical staff.

Testing for hepatitis B and C was part of our routine hepatitis surveillance blood samples and as such required only verbal consent. However, patients had been kept up to date with NANB hepatitis (HCV) developments through the Unit staff and the Haemophilia Society Bulletins. Following the development of a blood test for hepatitis C NANB hepatitis became known as HCV.

Once a test for hepatitis C antibody had been developed patients who had been treated with blood products had a test carried out. An antibody test simply shows whether a patient has been exposed to a virus. The patients had been told of the development of the new test for hepatitis C and the need for testing discussed. Later in 1994, when the PCR test was available, patients were advised of this test being carried out, and of the implications of a positive result. The PCR test determines whether a patient is currently infected with HCV. A positive result indicates the presence of infection.

26. **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?**

Patients were given their test results by the medical staff. My involvement would have been to support the patient afterwards, if required.
Patients could be given their results;

- at their next routine clinic visit.
- at an earlier clinic visit.
- at an appointment requested by the patient.
- by letter.
- a patient drop in episode at the Unit.
- by a telephone conversation.

The patients had been tested for HIV and HBV and informed of their results before I took up post in 1986. There were no new cases diagnosed during my career in the Haemophilia Unit.

The HCV antibody test only told us if the patient had been exposed to the virus in the past. It did not tell us if the patient was still infected and carrying the virus. The patients were given their results at their next clinic appointment unless otherwise requested.

The HCV PCR test determined if the patient was still infected with the virus.

I cannot remember for sure whether we brought these patients back to earlier appointments or not.

Those patients who tested positive were given advice and information on the management of infection, modes of transmission (blood to blood contact and sex), advice on alcohol consumption, need for regular follow up, dealing with spillages and needlestick injuries and their prevention, use of condoms and testing of partners. Nursing support was available at the clinic and access to social work support could be arranged if needed. A range of pamphlets/information was available in the waiting area supplied by the Haemophilia Society and the British Liver Trust.
Examples of these were provided to the Penrose Inquiry.

Patients diagnosed with HIV, HCV or HBV were advised that they would require regular follow up at the Unit and would be seen by specialist doctors.

HIV positive patients would be referred to a specialist in infectious diseases from Ruchill Hospital (Dr Dermot Kennedy and then Dr Alan Pithie and then Dr Andrew Seaton).

HCV and HBV positive patients would be referred to a consultant hepatologist from the Royal Infirmary (Dr John McKenzie, followed by Dr John Morris and then Dr Ewan Forrest).

27. 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?

The patients were given advice regarding testing of partners, use of condoms (which were available in the Unit), safe use of sharps, dealing with needlestick injuries, dealing with blood spillages and who to contact for advice. If the patients had a problem or needed advice they generally phoned the Unit. If we did not know the answer to their query we would phone them back later with the information required.

28. 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?

The patients continued to attend the Unit for their haemophilia care. Infected patients were advised to tell their partners about their diagnosis. We were unable to do this without the patient's permission due to patient confidentiality. If the patient gave us permission, the partner could be informed by the Unit. We advised that partners be tested and this could be done by the Unit, their GP, at the Brownlee Centre or the Sandyford Clinic.

The Unit was happy to discuss any aspect of the patient's care as long as we had patient permission.

29. 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.

The following support was available to patients infected with viruses;

- Counselling means listening to someone and giving that person advice about their problems. Although the nursing staff were not trained in counselling we were always happy to spend time with the patients and support them in any way we could. This could simply have been just a cup of tea and a chat with someone who knew about their problems and with whom they could be themselves with no need to put on a brave face or hide the fact that they were feeling unwell, tired or scared.
- Staff nurse Elizabeth Little joined the Unit in 1988 and was an excellent communicator with the patients. She was able to put them at their ease and could discuss the most delicate of subjects with them. She would later become a well respected liver HCV nurse specialist at Gartnavel Hospital in Glasgow.
- Mrs Wilkie (counsellor) spent a lot of time with the HIV positive patients discussing their problems and practical issues of living with HIV.

30. 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.

Mrs Miriam Guthrie took over from Mrs Wilkie when she left. Mrs Guthrie was a senior social worker and worked with Judy Morris (I am not certain that this is the correct surname for Mrs Morris) to support the patients and their families. Judy Morris was replaced by Mrs Sheila Bowyer. Mrs Guthrie and I also carried out home visits to support the families of and the patients affected by HIV. Mrs Bowyer and I facilitated a self help group in the evening for some of the mothers of the patients. We organised a room where the mothers could meet and chat and we were available for general advice and information as required. They found this to be helpful and found support in each other. We facilitated it as long as it was needed.

The specialist clinics developed and expanded. The Unit staff were busy with the day to day running of a haemophilia unit. Sister Margaret Neilson was employed by the gastroenterology department as a liver nurse specialist in 1996 and worked alongside Dr John Morris who had taken over from John MacKenzie to care for our patients infected with hepatitis C. We handed over the HCV clinic to her. She had more in-depth knowledge of hepatitis C and its treatment and had access to more services for the patients. She spent a lot of time counselling our patients.

The HIV clinic also developed and Dr Kennedy was replaced by Alan Pithie and then Andrew Seaton. The clinic was moved to the Brownlee Centre where the patients had access to specialist nurses and a dedicated psychologist named Dr Wong and a dedicated pharmacist (Isobel Gourley) who the patients and staff could contact directly for advice on medications, their side effects and interactions.

The UK Haemophilia Society and the West of Scotland Group were able to support the patients by answering questions, providing information and articles in their magazine "The Bulletin". Philip Dolan, Chairman of the West of Scotland Group, was a support and source of information for many patients. He would visit them at home or in the hospital and was at the forefront of the Infected Blood Campaign.

31. **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?**

Care of HIV patients:

- Patients were counselled, tested and given results by Dr Charles Forbes, Mrs Patricia Wilkie and Dr Gordon Lowe.
- Patients were referred to Dr Dermot Kennedy Consultant in infectious diseases at Ruchill Hospital.
- Clinics were run in the haemophilia unit by Dr Dermot Kennedy and assisted by Unit nursing staff and medical staff.
- Regular reviews were carried out with blood sampling and physical examination.
- Patients were commenced on Zidovudine (AZT) by Dr Kennedy, the only treatment available at the time.
- Pentamidine inhalations were prescribed by Dr Kennedy as necessary when a patient was at risk of pneumocystis pneumonia and carried out in the side room of the Unit.
- Mrs Wilkie left and Mrs Miriam Guthrie took over the social work/counselling of patients and their families.
- Patients were given information on the MacFarlane Trust.

Dr Alan Pithie, Consultant, took over from Dermott Kennedy and then Dr Andrew Seaton from Alan Pithie. Care of patients with infectious diseases moved from Ruchill Hospital to the Brownlee Centre in Glasgow. The clinics continued to be run in the haemophilia Unit but later moved to the Brownlee Centre where the patients had access to specialist nurses and doctors, a dedicated pharmacist (Isobel Gourley) and a psychologist Dr Wong.

Sister Laura Mathers, who was one of the nurse specialists in the Brownlee Centre, was able to carry out home visits to the more disabled patients. We had a very good working relationship with her and the other staff members.

Some patients were unhappy with the move to the Brownlee Centre as they had to share the facilities with people who had contracted the virus through drug addiction or their sexual preferences.

The patients received regular review and access to the best available medication. The treatment of HIV improved greatly over the years with the development of new drugs to suppress viral replication. Our patients had access to all the newdrugs.

Viral load testing was developed and as viral loads fell families started thinking about having children. Patients and their partners were referred to Dr Mary Hepburn Consultant Obstetrician for advice.

If a patient required hospital admission related to HIV they were admitted to the wards in the Brownlee Centre. The nursing staff in the Unit would phone daily for an update on our patient's condition. Patients who required admission for treatment of a bleeding episode, surgery or dental extraction were admitted to the GRI.

GRI admissions were visited at least daily by haemophilia Unit staff to support the patient, help with treatment and blood sampling and to support and educate ward staff as required on haemophilia treatment and its complications.

Gradually with specialist care, the development of antiviral drugs, improved treatment to prevent opportunistic infections and regular review, our patients' life expectancy increased. Today the patients are expected to live a normal lifespan.

Care of Hepatitis C Patients:

- Patients who had been treated with blood products prior to 1986 were tested for hepatitis C in 1991/1992 when the antibody test became available. This test determined whether a patient had been exposed to the hepatitis C virus.

- Those who tested positive for antibodies had a PCR test carried out when the test became available in 1994. The PCR test established whether the virus was still active and needed treating.
- Infected patients were referred to Dr John McKenzie and a clinic was set up in the Haemophilia Unit, supported by the Unit staff. Later Dr John Morris took over the clinic and treatment of the patients.
- Blood tests and physical examinations were carried out. The implications of their test results and management of the infection were discussed.
- Initially the only treatment available was Interferon monotherapy injections. The side effects were most commonly headaches and flu-like symptoms.

The Unit nursing staff were involved with the initiation of treatment as prescribed by medical staff and this involved discussing side effects, giving subcutaneous injections (teaching the patient or partner to give the injections), discussing safe use of and disposal of sharps and generally supporting the patient.
Interferon has many side effects including headaches, tiredness, muscle and joint pain, depression, irritability, anaemia, fall in platelet count (platelets are necessary to form a strong clot when bleeding from damage occurs), changes in thyroid function and changes in kidney function. It is important to see the patient regularly and to carry out blood tests to monitor side effects and alter doses as required.

- Regular blood tests were taken.

Patients were advised to use condoms and to avoid pregnancies as Interferon was thought to harm the foetus.

We worked under the supervision and guidance of Dr Morris. Sister Elizabeth Little and I continued working alongside Dr Morris until Sister Margaret Neilson was appointed as a liver nurse specialist in 1996. After a while Sister Neilson took over the running of the clinic and it eventually moved to another department within the Royal Infirmary (Sister Neilson provided a full statement to the Penrose Inquiry). We continued to liaise with her regarding the care of our patients. The patients had access to counselling, more in depth information on new and upcoming treatments, advice on benefits and the Skipton Fund.

Information was available both in the haemophilia Unit and at the liver clinic about the Skipton Fund and patients were encouraged to apply to the Fund and were given help filling in the forms.

Over time new and more effective medications were developed and the patients were prescribed the most appropriate according to their genotype. We received regular communication from Sister Neilson, Dr Morris and their team including, phone calls, clinic letters and educational meetings to update us on the latest developments. We kept in touch with our patients and their haemophilia care continued as before in the Unit.

Leaflets/booklets were available from the Haemophilia Society and the British Liver Trust on hepatitis C and these were displayed in the waiting area.

Patients whose infection had progressed or who required inpatient investigations were admitted to ward 9. This was a general medical ward with gastroenterology as its specialty. Dr John Morris was a Consultant in the ward. Again the Unit staff visited any patients at least daily to keep updated on the patient's condition, give support to both patient and staff and provide haemophilia care as required. We had a good working relationship with the nursing staff.

32. **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?**

There were times when the HIV and HCV patients were treated differently.

In the early days some general ward staff were anxious and unsure when an HIV+ve or HCV+ve patient was admitted to their ward. There was a tendency to use every available precaution even when not required. Ward staff would follow infection control guidelines. However, for example, no guideline existed for a patient admitted with a joint bleed and this would be where the anxieties arose. The situation improved as their knowledge of haemophilia and the risks of transmission of HIV and HCV increased. The Unit staff along with the infection control nurses were able to advise and reassure the ward staff of safe practice.

Some examples are listed below of the patients' experiences:

- Admitted to a single room with trolleys of gloves, aprons, masks outside when not necessary.
- Disposable cutlery and crockery and plastic cups at mealtimes when not necessary.
- Being called in for treatment at the dental department from the waiting area by the dentist or dental nurse who resembled a "spaceman" in their personal protective equipment

Some of the advice we gave is outlined below:

- Our advice was that if a patient was immunocompromised that they should be nursed in a single room with their own toilet facilities if possible as should a patient with an open wound, gastrointestinal bleeding or diarrhoea and vomiting.
- Disposable gloves and an apron or gown should be worn when taking blood samples or handling body fluids.
- A sharps box should be taken to the bedside for reception of used butterfly needles.
- Samples should be marked as "Dangerous Specimens" and double bagged prior to transfer to the laboratory.
- Disposable gloves and apron/gown should be worn when changing dressings.
- Contaminated linen should be placed in an alginate dissolving bag and then double plastic bagged and marked as contaminated prior to being sent to the laundry.
- Ward staff were always made aware verbally and through documentation in the nursing kardex and notes of a patient's virus status.

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

For health and safety reasons clinical staff dealing with patients infected with HIV, HBV and/or HCV were informed of the patient's status. The appropriate information was documented in the patient's casenote and nursing kardex. These documents were, of course, of a confidential nature and only made available to clinical staff caring for the patient.

Initially the care of these patients was shared by the HIV and HCV specialist medical staff and the Unit staff and clinics were held within the Haemophilia Unit itself. At this time we were all learning about the implications of a positive result, the treatments available from the specialists and doing our best to support the patients through this difficult time.

Through time the HIV and HCV specialists developed their clinics and the clinics moved from the Unit to other areas where the specialist nurses and doctors took over their care. HIV +ve patients were seen at the Brownlee Centre as were co-infected patients and the HCV+ve patients at a clinic within the GRI. We remained in close contact with these specialist staff and our patients and helped wherever we could with their care.

34. 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 infections, upon them and upon their families over the years.

The impact on the patients emotionally and physically was considerable. They were:

- anxious about their future,
- depressed and had little hope of a future
- angry and looked for someone to blame,
- felt isolated due to the stigma attached to HIV and HCV,
- sad due to loss of a normal life,
- guilty at not being able to work and support their families due to illness,
- afraid of what was to come,
- financially stretched due to increased transport costs for hospital appointments and increased heating bills.

The physical effects of the infections were many and included tiredness, depression, difficulty concentrating, susceptibility to infections, fungal skin infections, skin lesions, weight change, jaundice and swollen abdomen and legs.

The treatments often made the patients feel ill with tiredness, nausea, hair thinning, diarrhoea, mood swings and depression amongst many others. Some patients felt suicidal.

As knowledge of HIV and HCV improved, and treatments advanced, I think the patients thought that there might be some hope for the future.

The public became more supportive and understanding of the plight of the haemophilia population as they became aware of how they had become infected. Some patients remained angry and looked for someone to blame but there were others who were resigned to the fact that if they had not received the treatment that their lives could have been quite different or that they might have died from a major bleeding episode.

Section 5: Research

35. 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.

Throughout my time working in the Unit many patients were asked to take part in studies to verify efficacy and safety of treatments, inhibitor formation or incidence of cardiovascular disease in patients with bleeding disorders. Most of the medical staff would be involved with discussing studies with the patients. Patients were given information about the individual study, what their involvement would entail, given time to read information sheets and asked for consent, no pressure was put on patients to take part. Their part in the study was usually to answer a questionnaire and/or give permission for blood tests to be taken.

36. 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?

Please refer to my previous answer at Q35.

37. 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?

Previously untreated patients was a term used in the Unit. These patients had never previously been treated with factor concentrates or blood products. They were vulnerable to inhibitor formation. In the Adult Centre it would be unusual to have a severe haemophilia patient who was a PUP as most had started treatment at the RHSC or at another Haemophilia Unit. Most of our PUPs were mildly affected and picked up on family screening or would be a transfer from the RHSC who had never required treatment with factor concentrate, blood products or recombinant products.

The GRI took part in the PUP study, but I do not recall us recruiting any patients.

Section 6: vCJD

38. 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?

The UK BSE outbreak was a widespread occurrence that affected cows in the UK in the 1980s and 1990s. I remember watching harrowing pictures of ill cows on the national news. In 1996 vCJD was identified. BSE and vCJD were thought to be caused by the same infectious agent. The members of the UKHCDO became concerned at this point for the haemophilia patient group.

39. 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?

A patient who had been a recipient of a blood transfusion died of the human form of BSE in the autumn of 2003. The patient was not registered or treated at the Royal Infirmary Haemophilia Unit in Glasgow. It was not possible to tell whether the patient caught vCJD from the transfusion or from eating infected meat. This was the first case of possible transmission through blood transfusion and the point where we became more anxious about our patient group. Treatment with blood or blood products was thought to be an additional risk on top of the risk of eating infected beef

in the 1980s and 1990s. Patients with haemophilia were thought to be amongst those at increased risk.

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

The Unit carried out a look back through patient records to identify those who had received blood products between 1980 and 2001. A letter notifying patients of theoretical risk was sent out in 2001, another in 2002 and 2004. Public health precautions were put in place. Patients were advised not to donate blood, not to donate organs or tissues, to tell doctors and dentists of their "at risk" status to allow them to organise single use instruments. Patients were encouraged to contact the Unit if they had any questions or concerns and could be reassured by a telephone conversation or an appointment in the Unit with a member of the medical staff.

The Haemophilia Society both UK wide and the West of Scotland group were available for support as well as the Unit staff.

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

See answer to Q40.

In 2008 an elderly gentleman with severe haemophilia A died after a fall. At post mortem he was found to have evidence of the prion that causes vCJD in his spleen. It was discovered that a blood donor whose donations had been included in a batch of FVIII had died of vCJD. The elderly gentleman had been treated with some factor from that batch. Another letter updating patients on the latest developments and information on vCJD was sent out in 2009. Again patients were encouraged to contact the Unit for further information if they so wished.

The medical and nursing staff were happy to discuss this issue with the patients and we received many calls and drop in visits from patients.

Section 7: Effect on clinical staff

42. 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?

The biggest risk to the staff from the viruses was through needlestick injury or blood to blood contact or through lack of knowledge. The precautions in place in the 1980s are still practiced today with a few developments.

1980s:

- Covering cuts and abrasions with plasters/ dressings.
- Safe use and disposal of sharps.
- Use of disposable aprons and gloves when handling body fluids and blood. Being aware of needlestick policy and procedure.
- Good communication with other clinical staff.
- Labelling (Dangerous Specimen) and double bagging of blood specimens.
- Working in a safe environment and taking care when reconstituting factor concentrates.

2000s:

- More effective waterproof dressings are now available to protect cuts and abrasions and reduce need for daily dressings.
- Safe use and disposal of sharps remains high on the agenda of a ward managers' responsibilities.

- Personal protective equipment has advanced and is of better quality and more user friendly. Needlestick policy and procedure is still regularly discussed.
- Good communication with surgeons, dentists, ward and laboratory staff and other clinicians remains very important.
- All specimens are now processed as potentially dangerous by laboratory staff and so the "Dangerous Specimen" labels are no longer used but double bagging continues to prevent contamination if a specimen is broken or leaks in transport.
- Blood sampling practices changed with the introduction of safer methods. The Vacutainer system reduced the incidence of breakages and spillages and, therefore reduced the risk of needlestick injury.

- Working in a safe environment and taking care when reconstituting factor concentrates in a dedicated "clean room".
- Hepatitis B vaccination was introduced in 1985 for both staff and patients.

Transmission of viruses from blood/blood products was less of an issue but still a risk to staff when I worked in the Unit as all the products had either been heat treated or virally inactivated by other means. We did, however, always wear gloves when reconstituting and infusing factor concentrates and taking blood samples. We took the risk of needlestick injury seriously. With the introduction of recombinant factors in the 1990s this risk was eliminated.

GRO:C

43. 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?

Reporting complaints about staff or patient safety was never an issue for me. However, had a complaint or issue occurred our procedure would have been to;

- try and resolve it locally with the person involved.
- If necessary contact the staff member's line manager and voice myconcerns
- If necessary discuss with the Consultant in charge
- If necessary contact the RCN for advice
- If necessary make a formal complaint through the hospital complaints department.

Issues regarding patient safety would be dealt with differently depending on type of problem. Discuss issues with other members of staff at Unit meetings.
Take advice from Infection Control nurses or Health and Safety Department. Take advice from the Consultant in charge, line manager or RCN.

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

The patients had already been diagnosed with HIV when I took up post in the Unit and so I was aware that I would not only be learning about haemophilia, its treatment and complications but also about HIV and AIDS. I knew there was a lot to

learn and there would be hard times ahead. The medical staff Dr Forbes and Dr Lowe had already told the patients of their diagnosis and that must have been one of the worst jobs imaginable. My job was to do the best I could for these patients and to support them through the difficult times ahead.

It was known that many of the patients had been infected with hepatitis and as hepatitis C was diagnosed in the 1990s it became clearer the impact this virus was going to have on the patients in the long term with the possibility of cirrhosis and hepatocellular carcinoma. Again there was a lot to learn.

Professionally, I had gone from caring for patients for a short period of time nursing them through the acute stages of their illness. I knew them and cared for them for a short period of time. Now I was looking after a completely different group of patients with a lifelong condition some of whom were facing the serious complications of their treatment. I would get to know them and their families well.

I was not only continuously extending my knowledge of bleeding disorders but also learning about HIV and HCV, care of the chronically ill, care of the dying and infection control issues and developing many new practical skills.

Caring for the patients was challenging. We were learning about the viruses all the time. Initially treatments were limited and the side effects made the patients feel unwell. This was upsetting and frustrating for us as we wanted to make the patients feel better, not worse. It was distressing to see them suffer both physically and psychologically as the diseases/infections progressed. Some days we went home emotionally exhausted.

Gradually the situation improved, our patients were receiving the best of treatment from the HIV and HCV specialist services. We were hopeful of the future for them. HIV patients had undetectable viral loads and HCV patients were clearing the virus and for this we were grateful. The Unit staff worked together through some harrowing times but we supported each other through the hard times and were thankful for the advances in treatments that we saw and were part of over the years and for the successes that we witnessed.

Section 8: Other Issues

45. Were you aware of any of the trusts or funds that were set up to provide financial assistance to people who had been infected (such as the Macfarlane Trust, the Eileen Trust, the Skipton Fund and the Caxton Foundation)?

We used the MacFarlane Trust, the Skipton Fund and the Caxton Foundation and although I knew of the existence of the Eileen Trust I do not remember having any dealings with it. We supplied the patients with contact details and helped them fill in the forms. We encouraged them to make contact with the funds.

46. Were patients at the Centre provided with any information about these organisations or with any assistance to obtain financial support from them? If so, what information and/or assistance was provided?

The medical staff would fill in the appropriate section of the forms providing as much information as possible to allow the patients to receive payments. We would photocopy the forms so that the patient had a copy to keep, and the Unit had a copy for the patient file. If the fund/trust had any queries or required more information we would try to deal with them as soon as possible.

If the patients requested access to their case notes this would be accommodated through the legal department.

47. Please detail any involvement or dealings you had with any of these organisations.

Please refer to my answer to Q46.

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

Medical records were held within the Unit indefinitely. Current, non current notes and those of deceased patients had always been kept on the Unit securely under lock and key. Medical Records were aware of this. This allowed 24 hour access to case notes if a patient was admitted as an emergency. The notes contained information on family history, baseline factor levels, inhibitor history and treatment records all of which are important when dealing with an inherited condition. Had the notes been

retained in the medical records department and been destroyed after the defined retention period a multitude of important information would have been lost.

Having treatment records as far back as the 1970s was invaluable in helping trace patients who had received blood products and required testing for viruses and also when filling in forms for the MacFarlane Trust and the Skipton Fund.

49. 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?

Apart from the medical record, information held in the Unit included details of the factor usage from the past in the form of the "Annual Returns' ' for Oxford.

At first this was in paper format and was sent to Rosemary Spooner in Oxford annually as part of the UKHCDO data collection, but later it was in electronic format and the information was collected and input by our Operational Manager, Mrs Nancy Brodie, on a daily basis.

The Unit had a database in which it held basic information on the patients such as bleeding disorder, baseline level, inhibitor status, virus status and treatment of choice plus a treatment plan.

50. 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 46 above, please provide (to the extent that you are able to) details of those discussions or conversations or interactions.

Over the years there were many times when the staff discussed treatment plans, factor usage, and how to develop and improve the service for the patients. We had educational meetings when we would discuss difficult cases, updates from meetings attended by members of staff, available treatments and their use, and we would have guest speakers from other departments to update us on treatments and developments in HIV and HCV. We also held meetings with the patient support groups such as the Haemophilia Society. We also took part in Scottish and UK wide audits.

51. **Please provide, in as much detail as you are able to, information about any other issues associated with your work at the Centre that may be relevant to the Inquiry's investigation. You will find the Inquiry's Terms of Reference and List of Issues on the Inquiry's website www.infectedbloodinguiry.org.uk. If you are in doubt as to whether or not to include something, do not hesitate to contact the Inquiry Team.**

Within this statement I have endeavored to give a clear and comprehensive account of my experience as a Haemophilia Sister within the Royal Infirmary, Glasgow. Many of the questions refer to times/events which took place before I took up the post in 1986. However, I have tried to give an account of what happened as I understand it. Although most of the questions refer to events which occurred many years ago I have tried to answer as clearly and accurately as my memory allows. I do hope that from all the statements submitted that we are able to bring answers and subsequently closure to the difficult and distressing period of time which has affected patients, their loved ones and the staff who were involved in their care.

Statement of Truth

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

Signed GRO:C

Dated 12/11/2020

Table of exhibits:

Date	Notes/ Description	Exhibit number
	Penrose written statement	WITN0920002