Tuesday, 17 November 2020

(10.00 am)

SIR BRIAN LANGSTAFF: Good morning, Dr Al-Ismail. Can you see me?

THE WITNESS: Good morning to you, sir, yes, I can see you.

SIR BRIAN LANGSTAFF: Let me start by saying a few words before I am going to ask you to take the affirmation. It would have been far better, as I think everyone who is watching, and you yourself may well agree, if you had been able to come in person. Plainly you can't because of the Covid restrictions which we have. But it has had this effect, that there are very few people in the hearing room. And I'll describe that to you in a moment or two, just as I will describe to those who are watching remotely who might have wanted to be here to see you in person, what the position is so they can visualise it and they know where you are.

You are, I think, in a hotel, and there is a member of the Inquiry staff -- and nobody else -- in close proximity but not so close that it's dangerous. They are keeping proper social distance. Is that right?

THE WITNESS: That's correct.

SIR BRIAN LANGSTAFF: So in this hearing room you can't

see, but you will in a moment, counsel to the Inquiry, Ms Richards, who will be asking you the questions. Behind and beside her there are two members of the Inquiry legal team, again at safe distance. We have three members of the Inquiry staff watching and a technician. And we have Mary, who will give you -- who will ask you to swear the oath.

The reason I'm mentioning this is because you need to know who you are talking to immediately, but you're not just talking to us. This is a public inquiry, and I said right at the start of the Inquiry that we would be putting people at its heart. And for that reason you might normally have been expected to sit at the desks in the Inquiry room in the centre of the room talking directly to a number of people in front of you. They are not there in person but they are there virtually because a lot of them will be watching. It will be about somewhere between 150/200 people, thereabouts, who will watch during the day, and there may be more who will pick up what you have to say remotely. So you are talking to a lot of people even though there are very few people here.

I want you to understand that and I want those people who are listening to understand too who is here, what your position is and that it would have

been my wish that they could have attended in person had they wanted to. This is, however -- it is important, as I said again at the start of the Inquiry, not just to put people first but also to be as fast, as reasonable thoroughness permitted, in coming to a conclusion, because people have waited too long to know what an inquiry like this would have to say.

That's why we are continuing our work during the pandemic and that's why I'm giving you a description, so that they understand what's happening here, you understand what's happening here, we have to be here because this is our place of work, and that's where we start today and where we will go on throughout the week.

THE WITNESS: Thank you for explaining that. Thanks very much for explaining that. And I would have wished to have been there but, as you already explained, there are circumstances which are beyond our control.

SIR BRIAN LANGSTAFF: I'm going to ask Mary to administer the oath to you. I understand you want to affirm so, Mary, would you, please.

DR SAAD AL-ISMAIL, affirmed

Questioned by MS RICHARDS

MS RICHARDS: Good morning, Dr Al-Ismail. Can you see and

hear me?

A. I can see and hear you. Good morning to you.

Q. I'm going to start by asking you to give us an overview of your career. You took up your post as a consultant haematologist with West Glamorgan Health Authority in June of 1982?

A. That's correct.

Q. Where had you worked prior to Swansea?

A. Okay. So I qualified in Baghdad, Iraq, in 1970. I did one year of what we call internship, where you would rotate between different specialities, and the idea really is to give the junior doctor the opportunity to have a taste of what medicine, obs and gynae, surgery -- and I also chose paediatric as a fourth three-month rotation. Then I chose to go into medicine. General medicine, that is. I did nearly four years of general medicine and then I came, toward the end of the fifth year, to the UK to do some postgraduate qualification, that's the membership of the Royal College of Physicians, and have a taste of what -- the UK system. So I took a few locums and had a taste of what general medicine and I also did a locum in paediatrics.

And then I passed my membership, the Royal College of Physicians, both Ireland and the UK, and

then I decided to go into haematology. And the reason for that is partly because I've already tasted haematology when I was working in the teaching hospital in Baghdad and I liked what I saw there. So I applied for a haematology job which came up in Cardiff, as a Senior House Officer in haematology. So I took that job, and I think it was 1 June 1976. That job was actually entirely based on what used to be called ward A7. That is the haematology ward.

So my tasks were really to work with the registrar and the senior registrar to look after the in-patients. And the vast majority of them were patients with haematological malignancies, but we would see the occasional patient with bleeding disorder. At that time I was taught how to prepare and administer cryoprecipitate. Also we used to take blood samples from the patient.

I finished that one year, and then Professor Allan Jacob and Dr Jack Whittaker -- or Professor Allan Jacob, who was the, if you like, head of the department, asked me if I could stay for another year, and they found me what's called at the time a leukaemia fellow -- they had some money from the MRC -- and I worked as a leukaemia fellow for one year.

After that they've asked me to apply for the -- they had a vacancy of a registrar in haematology, so I applied for that and I got it, and then there was a vacancy which came up after -- I think 18 months after that, as a senior registrar, and Professor Allan Jacob persuaded me not to leave, and stay and finish my training in haematology and apply for the membership of the Royal College of Physicians, whereby you'd be accredited as a fully trained haematologist.

So I did that. And I think just before I sat my exam in 1980 I was appointed as a lecturer in haematology, and I sat my exam in 1980.

Then I was in two minds whether to go for an academic degree, an MD or PhD, and then the opportunity came in and I -- I don't know how I was persuaded but I was persuaded to go to Swansea to apply for a consultant haematologist. And I joined my colleague then, Dr Khurshid, Mohamed Khurshid, who was appointed in 1975.

As I said in my statement, prior to that Swansea did not have a haematologist as we know it. All the haematology work was supervised by pathologists, whether from the general pathology or from the histopathology, and patients with bleeding disorders were very much under the direction of Cardiff and --

as what to give. But when Dr Khurshid came to Swansea, he was persuaded by Professor Bloom to take more active role, and I think the rest of it follows from there.

But perhaps I'll stop here until you want me to continue on the same theme.

MS RICHARDS: I'll ask you a little more about that in a moment, but just sticking with your own training, in those years in where you were working in Cardiff, prior to taking up the post in Swansea in 1982, to what extent did your work involve the care and treatment of those with bleeding disorders in Cardiff?

A. Okay. So, as I said, in the first year the only encounter would be for the in-patients who would come under Professor Bloom, would need to be treated for haemophilia and other bleeding conditions. But when I became a registrar, it was as a registrar then you rotate between different specialties of the haematology. Until that time, my work was mostly to do with haematological malignancies, but when you became registrar then you would do three months of coagulation and haemophilia and then three months of day unit, three months of laboratory, and so on and so forth.

So when I did my three months with

Professor Bloom, both as registrar and senior registrar, my task would be to actually go and see all the in-patients with haemophilia and allied disorders, go down -- what I used to do, if I was not on call I would go and ask the registrar on call whether he had any admission during the night, and if so I'll go and see the patients and then go and brief Professor Bloom. And Professor Bloom always would then come and see them and, you know, sort of give me the instruction to -- what to do in terms of management plan and whatever.

But he -- even though the number of patients were, you know, in single figures really, never more than four or five at any one time, and sometimes none, he used to spend quite a good time, actually, to go around and speak to them. His habit was to see the patient -- you know, examine them, and then usually sit by their bedside and talk to them.

Then I would go down to the laboratory after I've done my task in terms of preparing whatever needed to be prepared, and then start to learn about the laboratory side of coagulation. I was introduced to the different laboratory tests. And once I've, you know, sort of been shown how to do them, then I was given, you know, stuff as a tool, a rack and whatever,

and I was given, you know, sort of different reagents and asked to do the tests.

So that's how you become to know what these tests mean and how to interpret them. I would be called by the haemophilia nurse to see a patient who is attending as a day case. And initially I used to go to Professor Bloom almost with every single case, ask him what are the plans. He was a superb mentor, really, because he would explain and -- he would explain how to examine a joint in a haemophiliac and explain the principle of management. So he used to spend quite a lot of time teaching the junior staff how to deal with haemophilia.

You know, when you are on call you may be called during the night to administer, because the on-call in Cardiff was also responsible to administer the coagulation factor concentrate or the cryoprecipitate and there were many nights where I would be called to administer.

I remember one particular night -- the reason why I remember it is because it was quite late in the morning about three or four o'clock when I was called to come and see a patient who -- and the management plan was to give cryoprecipitate -- I don't remember the detail of the patient. But I remember the day

because I was flagged down by a police car and when I asked them why they flagged me down in my little Datsun they said, "You were driving too slow". So I learned that probably when you drive at night in Cardiff you have to go a bit faster.

But anyway so I remember that. The one thing I remember about preparing the concentrate, the cryoprecipitate, is that this is the one thing which probably will take the longest time for a registrar to do because I timed it at one time and it took me about just under two hours from the time I reached the hospital to thaw the cryoprecipitate, draw it up, and record the units which have drawn up in the patient notes.

Professor Bloom was very -- he was gentle but he was very strict in making sure that whatever we do in terms of units and batches and whatever has to be recorded in the patient notes. So you cannot leave it until the next day. But the cryoprecipitate used to take the longest time to prepare and give to the patient.

Q. I'll come back and ask you about Cardiff's policies, Professor Bloom's policies and Swansea's in a few minutes. Just picking up on your career you worked with Dr Khurshid at Swansea 1982 to 1985 and then when

Dr Khurshid left in 1985 you became the director of the haemophilia services.

A. Yes, that is not something you apply for. It's something which you take on because I was left, if you like, single-handed for about two or three months until Dr Beddall came. When I started in 1982, Dr Khurshid was a director. In fact, I could not remember so much of that so I had to give him a call when the Infected Blood Inquiry asked me under rule 9 to give the history. So I've asked him what was the history and he told me that when he first started, Professor Bloom -- he then was Dr Bloom, and persuaded him that he need his assistance to provide a better care for the haemophiliac living in the vicinity, even though he told him that he will be guiding him all the way in terms of things beyond what Dr Khurshid was familiar with.

He initially told him, "Look, we will make you a subcentre" but, in fact, there wasn't anything like called subcentre, but that's what Dr Khurshid told me that's how Arthur persuaded him to actually take it on. But then Swansea was given the full title of haemophilia centre and I think the number 151.

So when I took over in 1982, prior -- 1985, sorry. Prior to taking over, Dr Khurshid would

receive any communication from UKHCDO and he would -- after we finished ward rounds, whatever -- he would say, "Saad, look, we've received such and such communication and whatever", he would show me what he received. So, if you like, we tried to brief each other. So I would have briefed him about any leukemic or any patient with a haematologic malignancy. Similarly, he would brief me about any haemophiliacs and that was essential because you could be called at any time. I mean, the way it worked before I reached there, Dr Khurshid was literally on-call every day. So when I got there -- so we agreed to share the on-call and so you could be called at any time about a patient. So you really have to be very familiar with the patients in terms of there would be a known management plan of what the patient should have.

Prior to coming to Swansea, I think we were taught by Arthur that for children we try to give NHS concentrate because it was felt that they may be -- you know, sort of home-made concentrate, they are safer. To be honest, I did not question that until many years later. I thought must be something known about the imported concentrate. But, anyway, so we were told that children, try to give them NHS concentrate. If they need concentrate, that is

a severe haemophiliac, try to use cryoprecipitate. When DDAVP became available initially we didn't take DDAVP very quickly, I think, in the 80s. We started DDAVP in Swansea, I can't remember exactly when.

Q. I'll come on to the returns and we can see that.

A. Yes.

Q. You remained director until September 2015 when Dr Percy joined and then you took over the role of director, again I think, at the end of 2016 when Dr Percy moved to a different job and then you retired from the NHS as a consultant and as director of the Swansea service in February 2018.

A. Quite, that's true.

Q. Your statement says that the treatment of patients with bleeding disorders was only one part of your overall work. Your main specialism during your career was blood malignancies, haemato-oncology?

A. That's true.

Q. Very roughly, if we're thinking about the 1980s, what kind of proportion of your time was spent dealing with patients with bleeding disorder as opposed to patients with haematological cancers or general haematology?

A. I think I put in my statement 5 per cent but that is probably quite an optimistic estimate actually. Would it be helpful if I give you when I first started, very

briefly, my weekly schedule?

Q. Yes.

A. Then you could probably be -- you know, sort of have a clearer picture. So on Monday I would go to Neath General Hospital for the haematology out-patient clinic and we used to do that together with both myself and Dr Khurshid. We continued to do that until -- I'll come back to it later on -- when I thought we need to divide the work more when Dr Khurshid left. So I'll do a haematology out-patient clinic on Monday in Neath and then I would go and see with Dr Khurshid the in-patient in Neath because, unfortunately, initially we admitted patients with whatever haematologic condition in any of the three sites and then I would jump in the car and then go to Morriston. In Morriston, I would go and see the patient who may have been admitted over the weekend, see the in-patients, look at the blood films and whatever.

Then on Tuesday we will start again in Neath because until the reorganisation of the cancer services we also were dealing with haematological malignancies in children. So we would go to Neath to do the leukaemia and we used to divide that. So one week would be myself, the other week would be

Dr Khurshid. The other person would go to the other hospital, so I would go there and see the patient with leukaemia. The one thing about acute leukaemia in children they would have treatment every week for most of the time, so you would need to be there. You need to be there to administer the treatment because at that time we didn't have any junior staff, it was just the two consultants. We didn't have any specialist nurses but there was a consultant paediatrician, Ryan Griffiths, in Neath who was very keen that we help him manage the patients with acute leukaemia. So we used to use what used to be called the MRC trials so we go on the same schedule.

Then, once I would finish that, then I would go and look at whatever blood films left over from the clinic on Monday in Neath before going to Singleton to do a very large clinic, which was a Tuesday out-patient clinic.

On Wednesday, I would start in Singleton, see the in-patients, and then see the blood films of the clinic the day before and then travel to Morriston to see the in-patients in Morriston. We used to do the ward round in Morriston on Wednesday afternoon both myself and Dr Khurshid.

On Thursday, it would be the morning in new

out-patient clinic in Singleton and then in the afternoon it would be Morriston, and on Friday is the out-patient clinic in Morriston, and in the afternoon it's seeing blood films and whatever, seeing all the refills.

The one thing which probably would horrify any haematologist now is that the out-patient clinic we also used to give all the day case chemotherapy, do all the blood letting, what we call venesection for patient who need it. So the out-patient clinic would double as a day unit because we didn't have any day unit.

I've looked at the figures and I estimated that in one year I would have seen anything between 3,500 to 4,000 episodes. Now, I thought if I see two patients with haemophilia, which was very, very unlikely, a week then I would see about 100 patients a year. As I said, the estimate of 5 per cent was maybe an optimistic estimate.

So the haemophilia work was not really a big part of my duties. The unfortunate thing when I first started is that the only place to give treatment to haemophiliac would be either as an in-patient or, if we needed to give the patient as a day case, the patient has to come to the adult ward -- the adult

cases or the paediatric ward and then we go and prescribe the treatment.

In the paediatric side, the paediatric team would agree to do it. In the adult side, it depends. If there's no junior staff, then we would have to put the Venflon in and give the treatment.

That continued really until after Dr Khurshid left and it was clear that we could not continue when Dr Beddall came in. We sat and had, you know, a long chat and we agreed that we divide the work a bit more and then I spoke to Professor Bloom and he said, "Saad, you really need to get a haemophilia nurse". Then it took me two years and we got the haemophilia nurse in 1987 and that is when things start to change.

So this is a very long answer to your question but really, just to put it in some sort of perspective, as when I first started as a haematologist in Swansea what were my duties.

Q. Your statement has told us that most of the haemophilia care that was provided was at Morriston?

A. That's true.

Q. As you describe, patients were treated on the ward because there weren't any designated rooms or facilities for the care of patients with bleeding disorders?

A. That's true.

Q. As I understand it, there were not dedicated bleeding disorder out-patient clinics in the 1980s?

A. No.

Q. They were general haematology clinics?

A. Absolutely. They really -- a patient would be seen in a general haematology clinic and, even though the haemophiliac would take a longer time than an average patient, because most of the average patients is either repeat prescription or just telling them what their blood look like, but for the haemophiliac you really have to ask about whether they had any bleeds since the last time you saw them, and whatever else, really. But they were seen in the general haematology out-patient clinic. We did not start to see patients in a dedicated haemophilia clinic until 1991, when we managed to get the current accommodation for the haemophilia centre.

Q. Your statement describes that the main coagulation laboratory was at the Morriston and you talked about the role of the medical laboratory scientific officers, MLSOs, at Morriston Hospital.

A. Yes.

Q. They kept a record of products used per patient; is that correct?

A. Absolutely. Actually, you know, sort of -- they are, in a way, the forgotten, you know, sort of people really, because they were instrumental in keeping record of treatment, making orders for the treatment, and there was -- one particular one of them who actually got interested in coagulation and he developed the different assays. So we really had very much the similar type of assays, laboratory assays, as Cardiff would have had, simply because of the interest of this one particular person.

And then he did his PhD in coagulation, with the help of Professor Bloom. And so when the haemophilia services moved, if you like, to be delivered mostly in Singleton, we thought it will be unwise to remove the expertise and the knowledge from Morriston, whereby all the assays had been done. And Morriston was instrumental because it was the largest hospital. It was the hospital with the largest casualty department. It was the hospital where the cardiac services was started. So you do need a 24-hour coagulation lab, if you like, to be able to cope with all the demands that these services would impose on coagulation and, you know, sort of blood testing and whatever.

So we kept the specialised coagulation test in Morriston. And to this date it is still there.

Q. It was in 1991/1992 that designated space for a haemophilia clinic was finally made available at the Singleton Hospital, and that's the point at which you started having dedicated monthly haemophilia out-patient clinics?

A. That's true. And probably prior to that there was another milestone, and that was 1987, because in 1987 I managed to get the -- a haemophilia nurse, a dedicated haemophilia nurse.

So the haemophilia nurse, when she joined in 1987, I don't think she really had an office, but she was instrumental in actually shaping the way we looked after the haemophiliacs. So when she first joined in, she contacted every -- she started with the severe haemophiliac. She contacted every one of them, told them that she's there, and asked them to come and meet her. And I think they used to meet either in the laboratory or one of the -- I think Dr Khurshid's room when he's not there. I can't remember the details. But she actually started to see a change in terms of the approach of the way we manage haemophiliacs. And she took over from the -- what used to be called the medical laboratory scientific officer, and then changed to the biomedical scientist after that, that role.

And I'm still to this date so grateful to the MLSOs at the time. But then she took the -- from them the, you know, keeping count of the concentrate we used and preparing the returns to the UKHCDO.

Q. You've told us in your statement that when you arrived in Swansea across these three hospitals in 1982, a home treatment programme was already established?

A. That's true.

Q. Did that include adults and children?

A. Yes.

Q. In terms of patients with haemophilia A, was home treatment only made available for patients who had severe haemophilia A?

A. Yes, the home treatment is only for severe haemophilia.

Q. We'll see -- sorry, carry on.

A. But we will come to that, and I'm sure -- there was one exception to that, and that is von Willebrand's disease, and we'll come to that in a minute I'm sure.

So the home treatment was for the severe haemophilia. And you could see from the returns, the way the returns are made, really, to say how much Factor VIII you use for in-patients and for home treatment and how much cryoprecipitate you use for in-patient in home treatment and whatever, both in

haemophilia and von Willebrand disease. But the home treatment was dedicated for the severe haemophilia.

The reason for that really is very simple: to be able to deliver home treatment, whether for an adult or whether for a child, usually a parent or guardian until the child learnt to inject themselves, you really need to have regular, if you like, administration, otherwise you will lose the skill. So home treatment is not suitable for mild haemophiliac. And even the moderate haemophiliac, who would only need occasional treatment, it's not suitable. It's only for the severe haemophiliac.

Q. But you also had a home treatment programme established with patients with von Willebrand's disease, as you mentioned?

A. That's true, yes.

Q. We'll look at the returns in a moment in relation to that. Treatment was not, as I understand your statement, on a prophylactic basis until possibly the 1990s?

A. Yes. I tried really to figure out exactly when, but I think if you do have a statement from Cardiff which will tell you when they started prophylactic treatment, we would have started prophylactic treatment either the same year or the year after.

Professor Bloom was -- and his, you know, successors as well -- actually kept us informed of any new development and any practice. And because we shared -- well, our patients were all, if you like, those who need to be seen regularly, were seen by Cardiff. So they would have visited Cardiff, they would have seen the haemophilia nurse there.

Our haemophilia nurse would have -- when we first appointed the haemophilia nurse, she had to go and spend some time in Cardiff to learn from the haemophilia nurse there, you know, what are the roles and responsibilities. A job description is one thing but to see it in real life is different.

So they kept in touch with each other and the haemophilia nurse would also attend the haemophilia nurses, you know, sort of meetings and whatever. So when Cardiff started, I would suspect that we started very shortly after.

Q. We're going to look at the annual returns for 1980 through to 1985, doctor.

Could we have WITN3761008, please.

If we could go to the second page, please. If we could zoom in on that top part. Thank you.

So we can see here, doctor, these are the annual returns for 1980. The centre is, in fact, identified

as Morriston Hospital. And you've correctly identified the centre number as 151. Director, Dr Khurshid.

We can get a sense of the number of patients treated. So, haemophilia A patients treated during the year, 19; von Willebrand's patients treated during the year, 4. And this obviously is prior to your arrival but when you are working in Cardiff.

Then we can see the figures there. Cryoprecipitate used in hospital, to a fairly substantial amount, 130,970 units. Not -- sorry?

A. Can I stop you there?

Q. Yes.

A. So these are assumed units. So the 130,970, if you divide that by a denominator of 70, because that was the assumption made, that each unit have got 70 -- each pack of cryoprecipitate would have 70 units of Factor VIII. Now, let's not go there because, you know, sort of we had quite an interesting discussion about this when I first arrived, but that was the assumption. So the 130,970, if you divide it by 70, it would be I think 1,000 --

SIR BRIAN LANGSTAFF: 1724, roughly.

A. Yes. So I think that's an important issue because if we had used 130,000, I don't think BPL could have made

any NHS concentrate. The similar thing when you would come to -- so that was used for the haemophilia A patients. And similarly when you come to the von Willebrand disease. I'm sorry to stop you there.

Q. That's quite all right.

A. I wanted to clarify that.

Q. So that's the usage of cryoprecipitate. We can see none used for home treatment for haemophilia A patients. And then we can see the figures for NHS Factor VIII: 8,167 in hospital, 46,629 for home treatment. And then we can see Armour Factor VIII, not used in the hospital at all, but 150,978 units for home treatment.

So the bulk of the home treatment in 1980 for haemophilia A patients was with Armour Factor VIII concentrate.

A. That's correct.

Q. And in terms of hospital treatment, the bulk of the treatment was with cryoprecipitate and some NHS Factor VIII treatment?

A. Yes, that's true.

Q. Then, as you've already observed, doctor, von Willebrand's disease patients were treated with cryoprecipitate at home and in hospital, and we can see the figures there: 77,000-odd in hospital and

70,000, in the way in which you have explained, those were worked out for home treatment.

A. Can I clarify one point here?

Q. Yes.

A. That the cryoprecipitate for home treatment is for the one patient. And let me explain a bit more.

We had very pleasant patient. I met her when she was 16, when I came to Swansea. And she had what we now call type 3 von Willebrand's disease. Now that is, if you like, a rare type of von Willebrand disease, inherited as a recessive character. And so she did not make any von Willebrand factor, von Willebrand antigen.

And consequently she would not have circulating any amount of Factor VIII. Because you need the von Willebrand antigen factor to carry the Factor VIII to maintain its half-life. So this is a patient who really had the most horrendous, you know, sort of experience in terms of bleeding because unfortunately she experienced both the symptoms of severe von Willebrand's disease as well as the symptoms of severe haemophilia. So she would have bleeding in the joints, bleeding in muscles but also nose bleeds, horrendous menstrual blood loss, and so on and so forth.

I've asked, you know, sort of -- because in von Willebrand disease, some of them -- well, afterwards, we used to treat them with concentrate, which caught a lot of von Willebrand factor, but unfortunately at that time the concentrate did not have substantial amount of factor.

Dr Khurshid explained to me that they have tried everything. Even though she was given mainly cryoprecipitate to be given at home, sometimes they had to supplement it with Factor VIII concentrate.

As I said, I met her when I first came to Swansea and she was 16. And she was the most pleasant patient you could have; even with all her predicaments she used to bring a smile whenever she used to visit the lab to collect her whatever. She was very popular. And she used to tell me that her life goes around cryoprecipitate, and I asked her what did she mean, and she said, "Look, I really can't leave home because of worry about a bleed. I have to give myself" -- and I looked at some of her returns for 1987, and actually she was having cryoprecipitate almost every day.

The reason I'm mentioning all this because, you know, unfortunately her life was cut short because of a bleed. And that was, if you would like to say, such

a simple bleed. She was in the city centre, she said that her legs gave way under her and she fell and she bled. By the time she got the cryoprecipitate, she had what we call a compartment syndrome. She had severe necrosis of the muscles. She was in renal failure when she was admitted to Morriston Hospital. I was there and consulted with the renal physician. I phoned Professor Bloom at the time and said that we have a serious issue here. So he asked me to keep him informed. To cut a long story short, the surgeon, the vascular surgeon and the surgeon came to see her, and they said, look, she's going to lose that leg unless we operate.

I really could not give that authority so I had a long chat with her and her family and she decided to go for surgery.

Q. If we turn on to the returns for the following year, doctor, 1981 -- it's page 6, please, of the same set of documents -- again, we can get a sense of the number of patients treated during the year, Dr Al-Ismail: 17 haemophilia A, six von Willebrand's. We can see, again, the figures for cryoprecipitate: 219,240 hospital, none used for home treatment for haemophilia A patients. And then we can see NHS factor concentrates being used for both hospital and

home, 34,200 and 27,720. But the predominant treatment again for home treatment is the Armour Factor VIII, 100,534 units there, and some used in hospital.

A. Yes.

Q. If we read across to the von Willebrand's. Again, we can see the figures there. The total used for home treatment is given as 110,600. Is that also for one patient, the same one patient?

A. The only person who had home treatment with the cryoprecipitate was that particular patient. And I asked the question: how did you manage to do that? And I think they managed to get her a deep freeze. I'm not sure whether the deep freeze was with a monitor and whatever. So she had a deep freeze at home and she used to give herself the cryoprecipitate. But as I said, her life revolved around cryoprecipitate.

Q. Then if we go to the 1982 returns, so this is the year you joined part way through the year.

It's page 13 of the document, please, Soumik.

We can see here the figures. And it would appear that the amount of cryoprecipitate used in hospital for haemophilia A patients substantially decreased this year, in 1982, and the treatment

predominantly used in hospital was NHS factor concentrates and Armour Factor VIII. Does that accord with your recollection?

A. Well, to be honest with you, my recollection of whatever 38 years ago is not -- so the figures are as what you would see it there.

We had quite a number of patients with von Willebrand's disease. None of them of the severe type. I would tell you that, even for the in-patients, I wouldn't be surprised that so much of that was used by this one particular patient but I'm sure the other also would have had some of it.

That year we had quite a good supply of the NHS. Just to say here, I mean, the motto was that get as much NHS as you could put your hand on. So the NHS supply was very much not in our hands. So if we were told that we've got having more NHS supply, that was very welcomed. But there were, you know, some fallow years where we had very -- we had much less than this. But, yes, these are the figures. And I think there must have been one patient who had some Cutter Factor VIII concentrate because the amount is only small.

Q. We can see under "Other Materials", references to FEIBA, 38,500. That would have been for a patient

with an inhibitor?

A. Absolutely. We had a child with inhibitor, and in fact most of the time he was treated with Factor VIII because you could swarm the inhibitor with Factor VIII. He was a normal child and, you know, sort of he wanted to play rugby, even though he was advised not to do that, and he had some severe bleeds. And I can't you exactly what was -- the FEIBA is, but knowing the particular patient, I wouldn't be surprised if it was not for severe bleed which they couldn't control with the Factor VIII. But I can't remember the full details.

Q. Do you know why, in 1982, and we see the pattern repeated later, cryoprecipitate was being used very little in hospital for haemophilia A patients as opposed to the previous years where it was still being used to a reasonably substantial extent?

A. No. I suppose it all depends on the patients. I'm speculating here. It all depends on the patient who needed it. Because we had a large family, a very -- quite an extended family with mild haemophiliacs. And even though they were mild haemophiliac, some of them actually develop inhibitor. And I suspect that -- but they were not high responder inhibitors, so you could actually swarm the inhibitor with -- sometimes even

with the cryoprecipitate. But like I said, without having the notes in front of me, I cannot give you exactly the reasons. But one possibility is that the milder patient had required more of the treatment, whether they were the milder patient with an inhibitor or not.

We had many more milder patients with haemophilia than severe patients. We only had a few severe patients.

Q. We can see that the treatment most given to patients with haemophilia A there is the Armour Factor VIII.

A. Yes.

Q. If we then come on to 1983.

Soumik, it's page 18, please.

We can see here, again, we get a sense of the number of patients treated. So 15 haemophilia A patients, two von Willebrand's patients. Again, a very small amount of cryoprecipitate used in hospital. But in this particular year there is more NHS concentrate used, so --

A. Yes, we had a good year.

Q. -- 209,995 for home treatment, 68,000-odd in hospital, and a smaller amount of Armour Factor VIII together with a small amount of the Alpha Profilate.

A. Yes.

Q. Would that change reflect simply what was available in terms of supplies or would there have been some other reason?

A. Yes. Yes, yes, that's really -- so that year we had 307,179 NHS and only 45,304 commercial. Yeah, I think that all depends of what we could get our hand on. And unfortunately I cannot tell you why should there be such huge fluctuation from one year to another. There was one letter which I remember which came from Tony Napier, but I can't remember the year, when he told us that because we used -- and when I said he told us -- not just in Swansea, he told us in Swansea and Cardiff -- that because we've used so much cryoprecipitate that our supply of the NHS concentrate was still reduced accordingly.

But even though we were using quite a lot of cryoprecipitate there in the home treatment, we had a fantastic year with NHS supply.

Q. Dr Napier was the director of the Regional Transfusion Centre in Cardiff?

A. Yes. So he was -- I mean, that was one of the advantages of actually working in South Wales, because Tony Napier was actually a senior registrar when I was an SHO in Cardiff and so, you know, having a personal relationship -- and later he actually asked me if

I could be on the advisory panel for the Blood Transfusion Service, and I think in the last year he was there.

But it was useful because you could pick up the phone and ask if you could have some more and you would get a polite no, if he hasn't got them.

Q. Then if we go to 1984, this is the first return that you complete --

A. No -- well --

Q. Page 23.

A. I have a correction here. 1984 it was still under Dr Khurshid but because these forms are completed, I think, in January of the next year, by then, then Dr Khurshid, I think, either have left or about to leave. So they put my name on it. So 1984 most of it was Dr Khurshid was the director.

But that year I've asked if we could change to packs rather than units. By the way, I think in 1983 your denominator for the cryoprecipitate became 80. So if you want to know the number of packs in 1983 you have to divide by 80, previously you have to divide by 70.

So this year we started using -- we started recording the packs and, as you can see, the home treatment, this is the one patient and also you could

see that she also had some NHS Factor VIII concentrate.

Q. We can see in relation to the treatment of patients with haemophilia A the primary treatment in that year appears to have been NHS Factor VIII concentrates, 157,540 in hospital, 240,620 for home treatment, and a smaller amount -- although still a reasonably significant amount -- of Armour Factor VIII for both hospital and home treatment?

A. Correct.

Q. So another year in which you had more supplies of NHS concentrate than you had previously; is that a fair inference?

A. Correct.

Q. Then finally, for present purposes, 1985 -- that's page 28, please, Soumik -- and we can see here 11 patients with haemophilia A treated, I think for the first year we see a carrier treated, and looks like is that three patients with von Willebrand's at the top of the page?

A. Yes, three patients.

Q. Then we can see for 1985 there is no cryoprecipitate being used for the treatment of patients with haemophilia A.

A. Yes.

Q. NHS Factor VIII is now reduced back down again, 50,390 in hospital, 75,000 for home treatment, and the main product, again, is Armour Factor VIII, 64,000-odd hospital, 2*23,440 units* for home treatment, and some Cutters Factor VIII Koate. We'll come on to look at the introduction of heat-treated products in a little while, Dr Al-Ismail, but to what extent in 1985, as far as you can recall, would the commercial concentrates there being used have been heat-treated concentrates?

A. Well, I think when the heat-treated became available, we switched very quickly to heat treatment and I must say that was very much with the direction of Professor Bloom. So as soon as the heat treatment became available, we switched to heat treatment. So the thing is about Swansea, unlike Cardiff, because we were a small centre we did not hold big stocks so, if you like, our stock would be used within a month. So when heat treatment became available, we immediately switched to heat treatment and -- you know, I was asked to say how did we do with the finance, and the problem is that I can't remember any problem with the finance. In fact, I can't remember signing any invoice. I contacted the people who were, you know, in the blood bank and whatever and asked them if they

remember signing any invoice and we were not.

I don't know. I think it's probably because we were a small centre, whether whatever allocation was given to the West Glamorgan Health Authority was accepted -- you know, whatever we ordered was acceptable with that requirement. But, as soon as the heat treatment became available, we introduced it.

Q. We can see towards the bottom of this return for the first time an entry for DDAVP and tranexamic acid. Is it fair to infer that this was the first year it was used, because there's no earlier reference in the returns?

A. You know, I honestly cannot -- I questioned that myself, how come that's so late in the day that we used DDAVP and tranexamic acid. It really all depends as to the person who's preparing this was made aware that DDAVP may be -- DDAVP was ordered, you see, to pharmacy. It did not come through the blood bank and so whether it was, and I suspect it is, that we did not convey that to the person who was putting these returns together, because I think we must have used DDAVP before then, because we simply had quite a large group of mild haemophiliacs.

But because this is the only thing could find on paper, then I cannot be certain about anything else.

Q. In terms of the mechanics of obtaining the various different products, you've told us just now DDAVP was obtained through the pharmacy, cryoprecipitate was that obtained directly from the Regional Transfusion Centre in Cardiff?

A. Correct.

Q. Do you recall whether there were difficulties in obtaining sufficient supplies or whether you usually had sufficient supplies of cryoprecipitate?

A. That I cannot recall. If you ask me have we asked for more and we were told we cannot have any more, I cannot remember any whether we did or we did not. Because I've got a feeling I could sense what your next question is going to be, is why didn't you switch more of your patients to cryoprecipitate and we could discuss that if you do ask it.

But I can't remember. As I said, we had such a superb relationship with the director of the Blood Transfusion Service and he was such a courteous and -- you know, the old ways, if you like, stood for Swansea, even though Cardiff was the main user.

So I always argued with him, you know, jokingly, that you only look after Arthur and, sort of, he would always dismiss that and he said, "I look after you more than I've looked after Cardiff".

So he is -- the quick answer to your question is I don't know.

Q. NHS concentrates you also obtained, as I understand your evidence, from the Regional Transfusion Centre?

A. Yes.

Q. You have told us effectively that -- is this right, please correct me if it's wrong -- that you would have wanted more and you took what you could get; is that correct?

A. Absolutely right.

Q. Were representations made by you or by Professor Bloom or Dr Khurshid or anyone else, to Dr Napier to try to get more NHS concentrates?

A. Well, I must say here the flag bearer was Professor Bloom because, really, he was very gentle but he was always fighting the corner for us to get more of the NHS concentrate. So I think if -- Tony Napier would tell us how much he gave us and how much he gave Cardiff, and if I felt Cardiff had too much more -- I know that they have much more patients so I cannot argue with that, but I used to say to Tony, you know, "Why don't we -- can't have more?"

But I'm sure if there were any noises made to higher authorities, it would have been Arthur.

Q. Now, in terms of obtaining commercial products, your

statement suggests that initially -- this is paragraph 64 of your statement --

A. Okay.

Q. We'll just put it on screen, in fact. WITN3761005, please, Soumik. Do you have some water available to you there, doctor?

A. I've got it, don't worry. Thank you.

Q. So we can --

A. I'm looked after well here.

Q. If we can go to I think it's page 20 please, paragraph 64. So paragraph 64, I just want to ask you about the actual arrangements, the mechanics whereby you obtained commercial products.

A. Yes.

Q. This suggests that the haemophilia centre in Swansea received blood products acquired on its behalf by Cardiff, initially, and then later on products were acquired via the West Glamorgan Health Authority, then latterly the Blood Transfusion Service.

Can you just explain a little more what you recall about the processes for obtaining commercial concentrates?

A. Well, I remember that, you know, Dr Khurshid told me that and the MLSOs told me that before Khurshid came in all the treatment was directed from Cardiff and

I think Cardiff used to send the product to Swansea, and then when Dr Khurshid came in, he ordered the products. I can't -- I wouldn't know whether it's via Cardiff or directly but the person who was making the orders from the blood bank, he told me that he distinctly remembers putting orders via West Glamorgan Health Authority for concentrates.

Then there came a time that we all agreed that whatever we need could be ordered by the Blood Transfusion Service and then the Blood Transfusion Service would supply whatever Swansea needed and whatever Cardiff needed, and then charge us accordingly. We found that as the very useful way for two reasons. One is that we would not come to any product which would expire. I remember during my time that very often the UKHCDO would send us a note saying, "Such and such a centre have product which is about to expire, can you use it?" We never faced that and the reason we never faced it simply because there was stock of supply held on our behalf by the Blood Transfusion Service.

For a certain time that arrangement were devolved to West Glamorgan Health Authority but then was taken by the Blood Transfusion Service and was taken by the Blood Transfusion Service until, to this

day, except for home treatment of recombinant, but we can talk about that later.

But if you ask me when every stage happened, I could not tell you and I tried to find out, unfortunately, all the records of the blood transfusions prior to 1984. We could not access them and we could talk about that maybe in additional questions you may have for me at the end. So I cannot tell you when the Blood Transfusion Service took the responsibility of stocking on behalf of Cardiff, Swansea, Newport and any other -- and Carmarthen in South Wales. We found that as the most useful arrangement, really, because we did not have to worry and if in the middle of the night you have a patient who requires a different concentrate and/or a patient who may be visiting Swansea for a holiday and you did not have any particular Factor IX or whatever, then you could pick up the phone and get in touch with the Blood Transfusion Service on call and get the concentrate. So that was most useful.

But I cannot dissect as when each stage happened.

Q. Between 1982 and 1985 when you took over as director, did you have any direct dealings, as far as you can recall, with the commercial pharmaceutical companies

to discuss products with them?

A. I think you reminded me about one of the reps, I think from Cutter, who came to see me -- I could not remember that -- and, of course, the rep from Armour. I did not have any contact with them prior to 1985 because Dr Khurshid was responsible for that. But in 1985 they clearly came to visit me. Whether that for me to put an order directly to them or via the Blood Transfusion Service, again, I cannot tell you.

As I said, I could not remember signing an invoice for Factor VIII. In latter years, when we had a recombinant, I signed all the invoices for the home treatment but not for the hospital treatment. But I could not remember signing the invoice. So, yes, I did see, but I think I only remembered when you reminded me in the letter.

Q. Just so that we see that, so there's no mystery about what we're referring to, we sent you some documents from Cutter, Dr Al-Ismail. BAYP0000007_080.

We can see this is a letter from a Cutter rep dated August 1985. It refers to a meeting with you and discussing your possible requirements for Koate heat-treated Konyne heat-treated and Gamimune. Then if we just look down to the fourth paragraph:

"... should you wish us to reserve batches for

you, we would be happy to do so. This policy is followed by eminent doctors such as Professor Bloom, the principle behind it is minimising patients' exposure to a large number of batches."

I'll come on to the general issue of reserving batches and reserving concentrates in a little while, doctor, but do you recall whether you did ask Cutter to reserve batches for you, or indeed Armour to reserve batches for you?

A. Well, I cannot recall but if Professor Bloom had asked for them I certainly would have done the same. If you ask me to recall, I cannot recall. I think what I recall after is that Arthur told me that he is falling out with Cutter because they could not reserve all what he wanted, but I think because we were a smaller centre he asked me whether we had a similar problem and I said no. So we must have reserved it but the mechanism of it I wouldn't be able to tell you now.

Q. Sir, I note the time and I am going to come on to ask the doctor in some detail about the treatment policies, so perhaps this is a good moment for a break?

SIR BRIAN LANGSTAFF: Yes, it is. What we do, doctor, is we take about a half hour break, 20 minutes to

half-an-hour in the morning. It's to allow you to have a break. You say you are being well looked after there but it gives people a chance to look after you again. You mustn't talk to anyone about the evidence you have given or may yet be asked to give you think. You can talk about anything else but not about your evidence. That applies to any break that there is.

A. Okay.

SIR BRIAN LANGSTAFF: It is also important not only that you have a break but that those in the hearing room do. And the third and largest group of people to whom this applies, those who are watching at home, would no doubt benefit by having the half hour as well. So we will take half-an-hour and come back at ten to 12.

MS RICHARDS: Thank you, sir.

SIR BRIAN LANGSTAFF: Ten to 12.

(11.21 am)

(A short break)

(11.51 am)

MS RICHARDS: Dr Al-Ismail, you told us in your statement that your general policy was to adhere to one concentrate per patient unless directed by Cardiff or there were infected batches. What was the rationale for the one concentrate per patient policy?

A. That was mainly to be able to identify if anything

untoward happened to the patient. And to be truthful, the main thing which were on our mind before the HIV and, later, hepatitis C identified, was the development of antibody. Because development of antibody in a patient with severe haemophilia is a real problem and a real difficulty. So adhering to one batch would probably reduce the, if you like, number of antigens -- or that was the thought behind it -- a patient may be exposed to.

So that was perhaps the main reason until the advent of the retroviral infection, in which case we needed to know exactly what batch would probably have contributed to the infection.

Q. Was that the policy when you began in 1982 in Swansea?

A. True, yes.

Q. Was that your understanding of Professor Bloom's policy in Cardiff?

A. Yes. I think he very much taught us to try to adopt that policy. The difficulty for me is to be able to say exactly when I've learnt such and such a thing, but I remember when I was a trainee there are certain things he explained to us that we need to think about when treating haemophiliac. One of them was to reduce the exposure to different batches and different products.

Q. There's one document I'm going to ask you to look at, Dr Al-Ismail.

Soumik, it's BYOP0000024_214.

This is an internal Cutter memorandum dated 8 May 1985 between two Cutter employees. If we go to the second page, please, the second paragraph, so towards the top of the page, records this:

"It must also be remembered that it is the policy of Professor Bloom to change suppliers once a year. This change was due last September and Cutter have held on very well to delay it until the end of March, 1985."

So this would suggest that Professor Bloom's policy was, as recorded there, changing suppliers on an annual basis. Do you recall that being his approach? Because it wouldn't be consistent with a policy of sticking to one concentrate per patient?

A. No, I don't know. I simply do not believe that whoever wrote that got it right. That was never, in my mind, the policy of Professor Bloom. I can't really comment as what was the reason behind the person writing that, but that is certainly not what he taught us and what he practised.

Q. You say in your statement, and this is paragraph 56(ii).

Soumik, it's WITN3761005, page 18, please.

At paragraph 56 you talk about certain general principles applied for selecting products. The first is all products were licensed products, and then secondly you say this:

"Safety and efficacy of a selected product for a patient would have to be a priority."

How was the safety of a product assessed from your perspective?

A. Well, maybe in retrospect it was probably a misplaced trust in the medicine licensing agency in the UK, in that we never used a product which is not licensed. We never used a product which has not proved to be efficacious. This is what the statement is based on, in that whatever we used were supposedly licensed, and to be licensed you had to have a safe and efficacious product. But, you know, that -- I mean, we could talk about that later on if you want, but that is our trust in the system in the UK, like you trust that system for any medicine you use.

Q. I'll come on at a later stage to talk about the risks of hepatitis with you, but paragraph 57 of your statement then suggests in the second sentence:

"... having discussed the issues with colleagues at the time, it would appear that perhaps financial

pressures may have played a part."

Could you identify for us the colleagues with whom you've discussed the issue and what the financial pressures are that may have played a part?

A. I did not discuss anything with the colleagues but, if you look at this statement, this is exactly the same wording that appeared in the Chief Executive statement in 1988 because I, you know, sort of helped in getting the information for the Chief Executive. The truth of the matter is that we went and asked whoever in finance and whoever was -- worked in West Glamorgan Health Authority whether they do remember if there were any financial pressure applied in terms of the haemophilia centres. They said they do not but they think they could have been because financial pressure were applied everywhere.

So I do not -- I haven't discussed with any particular person but when I've asked to -- because I've told them, look, I do not really know how we paid for this product, whether there were any questions mark raised by the finance director as worry -- nobody has at any time during my time in Swansea come to me and say, "You cannot order this", or "This is too expensive for us."

As I said, that may be because the haemophilia

centre in Swansea was a small centre. Talking to colleagues round the country, I think that was a hurdle -- everyday hurdle for them, really, to ensure that what they wanted they, you know, got for their patient.

So I haven't discussed with anyone in particular, but when I made the enquiries I said, "Look, I cannot remember, can you go and ask?" And I think contacts were made with whoever finance person they could get hold of who may remember the era, and they told them probably financial pressure were applied but no further details.

Q. You have said throughout your statement that you followed the advice of Professor Bloom in terms of the approach to treatment.

A. True.

Q. Had that been Dr Khurshid's approach as well?

A. Yes.

Q. How was the advice of Professor Bloom communicated to you? Were there regular meetings? Was it in writing?

A. Well, I think Professor Bloom really -- we were in regular contacts with him. You know, whenever we want to make any decision really. I'll give you an example, is that when we went to Cutter and I passed by him and he said yes, they okay if you could get

them to supply you on regular basis with the same products. When we wanted -- when I said, "Look, we really need to have a haemophilia nurse, would you help us", he was very helpful there. But we also -- I used to go to the meetings in Cardiff whenever I can but, I would say, from day to day, week to week, it used to be telephone contact. I knew that he -- when Dr Khurshid was director he received communication from him in terms of what policies they want us to adopt. I can't remember, and I did say in my statement I cannot remember or cannot get hold of a written policy, but the fact that I could not get hold of written policy did not mean that we did not have a policy. We had a policy but I cannot show the Inquiry a written copy.

But how did we speak to him? We could speak to him at any time. He was very available to us. And if there were any issues -- and whatever we've used he would have known about, because when a patient -- he -- you know, we used to make sure that he sees the severe patient at least once -- at least once a year. And if the patient has got any issues with joint and whatever, he could see them many more times. And if the patient needed any, you know, sort of input from their haemophilia nurse, before we had a haemophilia

nurse we could see the patient. He would know what the patient would be receiving, he would know what the patient had been treated, how much the patient is likely to use.

So the channel of communications were many, including, you know, sort of written letters and whatever. And you would find some letters from me and from Dr Khurshid asking him to see a patient because we are concerned about a joint or whatever. So the routes of communication were many. He did not have any hesitation in picking the phone and phoning any of us if he thinks that there are certain issues he wants to direct us to.

We used to invite him every now and then -- and I must say, it was before I started, the Swansea haematology department used to have a monthly symposium where actually we used to invite all the biomedical -- the MLSOs at the time, all the junior staff, colleagues from other departments, and we would have, you know, sort of buffet dinner and we used to invite a speaker, and Arthur was, you know, sort of a regular speaker. Mind you, he wasn't just a regular speaker for us, he would -- you know, he was regular speaker in other hospitals, really to advise them about haemophilia and whatever.

So many, many, you know, sort of forms of communication with him. But he was always available.

Q. So is this correct, Dr Al-Ismail: the general policies followed at Swansea were the policies of Professor Bloom, in terms of, "This is the kind of treatment you should give to a patient with mild and moderate haemophilia", et cetera; is that correct?

A. True. That's correct.

Q. In terms of the decisions as to which pharmaceutical companies to purchase commercial concentrates from, to what extent was that determined by Professor Bloom or taken by you or Dr Khurshid autonomously?

A. Well, that is the difficulty I had in actually pinning down exactly what happened. When you showed me the Cutter reps, so surely we must have ordered something from Cutter directly. But for most of the time the products we ordered were, you know, stocked in the Blood Transfusion Service and it would be a product that we used and Cardiff may have used. But, you know, if you ask me did he pick a phone and say, "Look, Saad, you really have to get in touch with this company and order", he never did. But, I mean, I cannot really be certain as, you know, sort of what were -- apart from what -- the letters you've kindly shared with me, I could not be certain as Armour, you

know, sort of clearly came and saw me at the time, but I cannot remember exactly. Profilate, we used some Profilate in 1987, if you look at the returns of 1987. And that was very much influenced by him, when he told me that Profilate, he felt, even though they were more expensive, they have got certain advantages. But then, you know, we found that after a while he stopped using Profilate because for one reason -- I think it was to do with the hepatitis C.

But he never dictated to us that we can only use that product. You have to remember that he really -- he really led, in terms of directing us, by his knowledge, and we respected, you know, sort of his authority so much. And that's not just us, mind you. I mean, you go to any international or national meeting and you could see how much he was respected and, you know, sort of listened to in terms of the knowledge he had.

Q. As well as following Cardiff's -- what you understood Professor Bloom's general treatment policies to be, you've referred to his role in relation to individual patients.

A. Yes.

Q. Was that predominantly patients with severe haemophilia A that he would become involved with or

was it patients of any category?

A. Well, patients of any category if they needed his input. I'll give you several examples. Before the advent of the HIV, if a patient with mild haemophilia in a sort of -- as I said, we had a group of mild haemophiliacs who unfortunately, even though they were mild, they would develop inhibitors. So we would have, you know, sort of shared that information with him, asked him for input. Patients who -- we didn't have any social worker dedicated to the haemophilia.

The social worker who helped us, very kindly, was a social worker who was assigned to look after the haematology in-patients, and the vast majority of these were patients with haematological malignancies. But she did actually got herself involved when we've asked her to look after the social aspect of haemophiliac when they are admitted, and she continued to follow them up. But most of the social worker input was from Cardiff. So if there were any issues, then I would pick up the phone or write a letter to Professor Bloom and ask for help or ask -- for example, training the parents, very often we would ask for the help of Cardiff in training the parents or training the child. There were certain children with needle phobia and they did have a programme -- which

was improved later on, you know, sort of the role play or whatever they called it.

So we did ask him for so many issues. But certainly in terms of any issues that we felt that we need his input and you would find letters from Dr Khurshid or myself asking him for an input in any particular patient. In other words, he was there. Whenever we needed any help, he was there.

Q. Did you always follow his advice or were there occasions when you disagreed and took a different course?

A. No, I think to have, if you like, ability to make your own decision, you really have to be very well informed. I think that is not just my motto, I think that's the motto of most of my colleagues. So I will be able to make a decision about a particular patient with haematological malignancy, who there are more than one option of treatment, if I felt that I really have all the information which I then could cascade to the patients and their carers and say, look, these are the options.

In terms of haemophilia, I think I know I could make a decision as when to treat a patient, when to do the levels, when to look for inhibitors, when to have a second thought that this patient joint is going to

be a problem, but I was not that informed as Professor Bloom or UKHCDO's working parties, so I would not think that it was right for me to take that decision. It really depends how confident you are with the information you possess, and it would be very wrong for me to say, look, I think I would take a different path from what Professor Bloom would advise.

Q. In terms of the actual treatment policies, your statement tells us that, and as we've seen from the returns Von Willebrand's patients were, generally at least, treated with cryoprecipitate and then, for haemophilia A, patients who were mild or moderate, your statement says that the policy would have been -- was to treat them with cryoprecipitate or DDAVP; is that correct?

A. That's true. Sorry, let me just explain a bit more. There are issues with DDAVP. DDAVP is effective in some patients and we actually did produce response for every single patient under our care but that only occurred not in the '80s but maybe in the '90s and 2000s.

DDAVP is effective in some of the mild patients depending on their base level. It could increase it to maybe 20 or 30 units, enable you to maybe have

a tooth extraction, but it would not be adequate if you are going to operate on a patient. The other problem with DDAVP is that, because of what we call tachyphylaxis, you lose the effect of DDAVP after a couple of days, and there are other issues about fluid retention and whatever.

So DDAVP is useful for the mild and probably less useful for the moderate but in some of them you do get a reasonable response, but only for a limited period of time.

Q. For patients who for whatever reason you didn't use DDAVP, either because, as the return suggested, it wasn't used until 1985 or for reasons that you've given that it was not appropriate in an individual case, would those patients then have been treated with cryoprecipitate as the first line of treatment?

A. Yes.

Q. Were there circumstances when you were at Swansea when mild or moderate patients were treated with concentrates?

A. Yes.

Q. In what kind of circumstances would that arise?

A. That would have been a surgical operation or surgical intervention and in one patient which I included in my statement he was a mild haemophiliac, in 1980,

I think, where he needed several teeth extraction under GA, and my colleague -- my ex-colleague Dr Khurshid -- gave him concentrate. In other words, when you felt that you really need to achieve a certain level and sustain that level for maybe a few days, the DDAVP would not be adequate.

With cryoprecipitate you could try but, if you have a patient undergoing surgery, you cannot really afford but to get them to about 100 per cent or what we call 100 units or whatever because of the fear of bleeding. So there were patients -- I remember one patient with mild haemophilia who insisted on having one of his -- I think the big toe was causing him so much problem he was seeing the orthopaedic surgeon and the orthopaedic surgeon said, "Look, we could correct that but it means an operation", and we chatted about the operation and I said, "In which case, we have to use concentrate, you have -- you know, it may expose you to other risk". At that time, to be honest, I was thinking more of Factor VIII inhibitor.

As it happened, he actually did develop Factor VIII inhibitor with the concentrate and I was so concerned about him at one time because he continued on bleeding and with the input of Cardiff we actually -- there was a programme which he used which

you take the plasma of the patient and exchange it. We had what we call a self-separator in Swansea, and it was a horrendous time. I'm glad to say that he's still with us and we often joked about his other foot, which again had the same problem and he said he may be thinking of having that done and, as I said, we joked about it saying "Do you remember what happened then?"

So the short answer to your question, did we use some concentrate for some mild haemophiliac: yes, if we had to undertake surgery where we think the cryoprecipitate cannot be relied on for certain to achieve the desired level.

Q. What was the treatment policy in relation to children, your statement suggests you think it was NHS concentrates if possible?

A. Yes. So NHS concentrate -- we talk about the severe haemophiliacs here because children with mild haemophilia could manage them with cryoprecipitate or even DDAVP after the age of two or whatever. But for the severe haemophiliacs we -- as I said, it was ingrained in us that NHS probably safer than the commercial concentrate. It turned out later on that, in terms of what used to be called non-A, non-B hepatitis, there isn't really much difference at all but, in terms of the HIV, there was a difference. But

that was all before the HIV and if you like the real and serious thinking about hepatitis C, and I'm sure you would ask me: what do you mean by "serious thinking"?

Q. I'll come back to that Dr Al-Ismail. Just sticking with the treatment policies, you said NHS concentrates because it was believed to be safer or that was the ingrained thinking. What was it at the time about NHS concentrates that led you to understand them to be safer?

A. You know, I mean -- to be truthful, I cannot remember exactly. You know, something which you have come to know but if you tell me which article or which information -- whether, you know, sort of that is what Professor Bloom have taught us when we were in training, maybe. It may be because we came across certain articles which I cannot remember now, could be, but it was something in our mind that if you could use NHS concentrate, use NHS concentrate. Mind you, some of them are so difficult to dissolve but we still preferred them to commercial.

Q. Your statement says you'd use the NHS concentrates for children, I think, if possible. Does that mean that if there were insufficient supplies of NHS concentrates you would have to use commercial

concentrates to treat children?

A. That's true.

Q. Then, in relation to previously untreated or rarely treated patients, your statement suggests that patients falling within that category would be jointly managed by Swansea and Cardiff and you'd consult Cardiff?

A. Yes.

Q. Could you just elaborate upon that please?

A. Yes, by all means. Fortunately for me, I did not have any new patient with severe haemophilia until the '90s but I'll use, you know, that incident to tell you what would happen. So this is a patient who was admitted and I was called by the paediatrician because there was an issue about whether it could be the patient was abused or whatever. Cut a long story short the first thing we do is coagulation profile and we find that he has clearly abnormal coagulation profile, do Factor VIII on the same day and Factor IX and his Factor VIII was less than 1 per cent.

Immediately pick up the phone and speak to colleagues in Cardiff to say, "Look, we've got a new severe haemophiliac, I'm going to see mother and father, and whatever, would you advise any particular concentrate, any particular product?" It depends as

what -- I think the patient I'm talking about was with the advent of the -- I can't remember when we were in the recombinant era or just before the recombinant, but with the safer concentrate. So I would call the family with the haemophilia nurse and whatever, and you actually have to take it in stages.

First of all, the state of shock because that family did not have anybody with haemophilia. They didn't know what haemophilia means. So you explain what haemophilia is, you explain it in simple terms, and you -- you know, draw a chart or whatever. And then you will talk about the need for treatment, treatment would be needed at some stage. They will ask you what to look for, "How do we know that our child would have a bleed?" And you explain all that.

And even at that time, you -- at that time where all the product were sort of HIV-clear, then I would say, "Look, we have different products, and I would be asking colleagues in Cardiff, which is the comprehensive care centre, would advise you very much to go and see them as well over there", and they always usually take that offer and they would make an appointment and see in Cardiff.

Cardiff was very good, really, in that they would see them the next day if need be.

So it would be jointly to do that. When we -- when Professor Bloom was there, and I gave you the example of the mild haemophiliac who developed inhibitor, I would immediately be on the phone to him and say, you know, sort of, "What would your advice be?" But for any previously untreated patient, I've -- it's not just me, myself and my colleagues felt that it is essential to explain to the family the availability of the comprehensive care centre.

Mind you, that's not just haemophilia. I'll give you another example. We used to see many more cases of leukaemia, and even though we are fully accredited in terms of treating leukaemia with intention to cure in adults, I still would say to the family, "There is a larger centre down the road from us and you are more than welcome to go and speak to them and see them and, if you want, the treatment to be there."

That was particularly true for the children, because Cardiff had a superb childhood leukaemia centre, and so many of them would have taken that on. Some of them, when they knew that it meant a weekly visit, felt that: look, we'll have the treatment here, but we want the help, the direction of Cardiff.

Sorry to enlarge on the leukaemia but it is, you

know, always essential to explain to the patient and their family what is available in Swansea and what's available in Cardiff.

Q. But as I understand your evidence, doctor, you didn't -- in the period 1982 to, let's say, 1985/86, when heat treated products were more widely available, you didn't have any previously untreated patients during that period?

A. No, I can't remember any patient. And I certainly did not -- I can't remember, even of the mild haemophiliacs, I didn't have any previously untreated patients.

Q. I'm going to ask you to look at a document, doctor.

Soumik, it's CVHB0000002_006.

You will see this is a document entitled "Haemophilia Treatment Policy Guidelines - May 1983". There's a date on the second page which is 18 May 1983.

This has been produced to the Inquiry by Cardiff, so it would appear to be a written treatment policy from 1983 governing Cardiff.

Do you recall whether you ever saw this at the time?

A. No, I -- you kindly shared that with me and, no, I can't recall seeing it. But this would probably

have -- if it was shared with Swansea, it would have been sent to Dr Khurshid. And I'm sure if Dr Khurshid had received it that he would have discussed it with me, showed me, because, as I said, I may be called in any time to treat a patient. So we were -- really wanted to speak in unison, me and him, as to what to do. But I cannot remember seeing that one. But if you ask me any of this information is new to me, no.

Q. Can we just look at a couple of the paragraphs a little more closely. In relation to mild haemophiliacs, it says DDAVP or cryoprecipitate or NHS Factor VIII concentrates. And you've already explained your approach towards mild haemophiliacs. Here, children with severe haemophilia, cryoprecipitate is put as the first order of treatment or NHS Factor VIII.

Your evidence to us has been that the treatment process was NHS Factor VIII and not cryoprecipitate for children with severe haemophilia.

A. No, I think if you look at the returns you'll find that some of the cryoprecipitate was used for in-patient. I really do not think that you can treat a small child with cryoprecipitate at home, so it has to be an in-patient treatment.

So if you have a small child whereby you could

give enough cryoprecipitate to deal with haemarthrosis, or you think you could do it, then you use it, you always do a post infusion Factor VIII. But if that is not adequate, then you have to use concentrate. And I'm sure that's what Cardiff would have used anyway, even though it's a -- when I say where feasible, that is exactly what it really means, that it is not always feasible.So if you have a small child whereby you could give enough cryoprecipitate to deal with haemarthrosis, or you think you could do it, then you use it, you always do a post infusion Factor VIII. But if that is not adequate, then you have to use concentrate. And I'm sure that's what Cardiff would have used anyway, even though it's a -- when I say where feasible, that is exactly what it really means, that it is not always feasible.

Q. We can see in (3), "Adults with severe haemophilia", cryoprecipitate, again, is identified "where feasible" as the treatment of choice for in-patient treatment, but we've seen from the Swansea returns that the use of cryoprecipitate declined in 1982 and 1983. Do you think you were following the order set out here?

A. I think so. And, as I said, 1982/83 was, you know, sort of very much under the direction of my colleagues, but I'm sure he was following what

Professor Bloom and the order in Cardiff was there really.

Q. But in terms of this actual document, you've got no particular recollection of seeing it at the time?

A. No, I don't. And I've seen the name on the document and I tried to figure out who's that and I still cannot.

Q. Again, I'm thinking about the period 1982 to 1985, in particular. To what extent were patients offered a choice about which treatments to receive?

A. In terms of cryoprecipitate or NHS or commercial?

Q. Certainly, by way of example, yes, to what extent would they be offered a choice?

A. I honestly don't know. I say I don't know because, by the time I joined, it was the same patient who was treated before that we carried on with their treatment. A choice is usually offered at the start of a treatment, so if I put the example of previously untreated patient, then I would explain to the patient and the family what products we have and what the advantages and disadvantages known to me at any one time of each product, and very often patient and family would say "What would you suggest, doctor?" And I think that is not just true of haemophilia, true of so many other conditions that, you know, sort of

when a person is faced with a choice and they do not really know what would be the best choice for them.

As I said in my statement -- and I think that's because I was more trained in haematological malignancies, and in haematological malignancies you truly cannot take a decision for a patient, and the reason for that, even with the conditions that are curable, the treatment itself may shorten the life of the patient because of its complication. So in haematological malignancies, you cannot take a decision for the patient. You can inform the patient with all the information you have at the time and try to get the patient to make the choice for you. Sometimes the patient would insist that they cannot make the choice so you turn to their carer and whatever and ask them to help, and you ask them, look, don't make today you can come and make the choice tomorrow.

I think that attitude toward haematological malignancy influenced my practice not just in haematological malignancy but in non-malignant conditions in haematology, whether that is in general haematology, and we have certain conditions in general haematology which are even more awful than haematological malignancies. So that influenced my

approach: try to say to the patient, "Look, I'm here to help you to make a decision but I cannot take that decision for you".

That certainly was my practice when I started to deal with haemophilia. But you've asked a simple question: do you know whether these patients were given a choice? That choice is usually explained right at the beginning of offering a patient any treatment. You explain what the treatments available, and if the patient come to you and say, "Look, I've heard in the news that such and such a thing could give me a problem, can you change me", you certainly would sit down and try to explain to the patient "Yes, I will change you but you have to go through the following".

But throughout my career no patient came to me and say, "Look, I've heard in the news about this product will cause such a problem, can I change to something different?"

Q. So is this right: in the period '82 to '85/'86 because you were dealing with patients who were already on a course of treatment, any conversation about choices would have been with Dr Khurshid or Professor Bloom, rather than with you?

A. Yes.

Q. I wanted to ask you about your knowledge of hepatitis.

A. Yes.

Q. First of all, what did you learn as part of your haematology training about the risks of transmission of hepatitis?

A. Well, from medical school, I think we knew about homologous CM jaundice, and then the Australia antigen and then hepatitis B and whatever, and we knew that blood could transmit viruses. We also knew, by the way, that blood could transmit malaria. That was the only thing which remained in my mind, until, I think, when I sat my MRCPath in 1980, I had to master everything, if you like. So I came to know that some patients who were hepatitis B negative would also have altered liver function test, but there are different views as what's the cause of that, some people called it non-A, non-B hepatitis, some people thought it's nothing to do with an infective agent. Interestingly, at the time, I wondered if it is an infective agent why somebody does not take the plunge and say non-A, non-B viral hepatitis, but nobody did that. They said non-A, non-B hepatitis.

So I knew of that but whenever you come in a discussion or whatever you were told that, look, this is probably going to be a mild problem because

it's not a big issue. I think I am right in saying that during the '80s, even though since the Inquiry came in and I've become more knowledgeable about publication before the '80s, you know, during the '80s most of us thought that non-A, non-B hepatitis is not going to be a big issue, is not going to be a big issue for the vast majority of patients. So this is -- you know, the initial knowledge I had about hepatitis was mainly hepatitis B but then this issue about patients with altered liver function tests.

Q. What, if anything, did Professor Bloom teach you or discuss with you about non-A, non-B hepatitis?

A. Well, yes, we did ask and he said he, I think -- he would have referred to all the publication which have happened and, I must say, you know, at that time I don't think any of them stuck in my mind for a long time until hepatitis C became known and whatever. But he would have told us about, you know, sort of what other -- you know, what the literature said and his opinion that, you know, sort of for the vast majority of patients non-A, non-B hepatitis is probably not going to be a big issue. But I don't think he was alone in that.

I think -- I remember that we talked about the liver biopsy which happened in Sheffield and we also

heard about a patient who died in the Royal Free because of a liver biopsy and we certainly, you know, sort of we felt that Professor Bloom was not a person who would be keen to do liver biopsy on a patient who had got this, what you call, non-A, non-B hepatitis.

But he would have -- I mean, as I said, he used to come and present -- in Cardiff we had always a Thursday lunchtime meeting. So people would munch their crisps while the presenter would present. You know, there used to be invitation for, you know, different speakers, even from abroad. Allan Jacobs was very well known in the haematology world, really, and so many of these talks would have been on haemophilia and allied disorders and, you know, sort of, so many of the presentation would have included some of the latest, you know, papers.

But if you ask me how much of that stuck in my mind later on, very little, I would think.

Q. So you have some recollection of the Sheffield biopsy work. We know that that was reported in The Lancet in 1978. Would you have been reading The Lancet in 1978 regularly or is that something you would have picked up from Professor Bloom?

A. Well, the journals which I used to get at home were the New England Journal of Medicine, the British

Journal of Haematology, the BMJ, and later on the -- Blood, the American Society of Hematology. The Lancet, if I need to read it, I would have to go to the library to read it. But, yes, I would have -- I don't remember reading the article but I remember that Professor Bloom told us about the work in Sheffield.

Q. What did -- I can show you the article if you want to but as you may not have read it at the time it may not be particularly useful.

Do you recall what Professor Bloom told you about what the Sheffield work showed or what the significance or otherwise of it was?

A. Unfortunately, no, I can't really, you know, sort of with any clarity tell you. I mean, it is all, unfortunately, mushed in the brain, 40 years ago.

Q. I am going to show you two short documents. You would not have seen them at the time but they're two expressions of you about non-A, non-B hepatitis and its nature. And I want to show them to you and then ask you again about Professor Bloom's views.

The first, please, Soumik, is BART0002487.

Now, this is part of the general material the Inquiry sent you but you would not have seen this, I think, at the time. It's a letter, April 1979, and

it's from Dr Kernoff at the Royal Free to Dr Colvin at The London Hospital.

If we could go to the second page, please, Soumik. And if we just go slightly a little further down the page, so we can see the whole of paragraph 2 please. Thank you.

So there is a long paragraph there under "Types of therapeutic material available", and I'm going to direct your attention, doctor, to one sentence. It's about two thirds of the way down, and it says -- well, two sentences:

"The clinical reason [this is for preferring NHS material] is the growing awareness of the probability that commercial concentrates have a higher risk of transmitting non-A, non-B hepatitis than NHS material."

I'm not asking you to comment on that, doctor. But then it continues:

"This [so non-A, non-B hepatitis] is a serious disease with long-term consequences ..."

Now that's the view being expressed by Dr Kernoff, who had a particular interest in hepatitis, to Dr Colvin.

Do you recall Professor Bloom ever discussing non-A, non-B hepatitis in these kind of terms, as

being a serious disease with long-term consequences?

A. Now if I say I don't remember, and I don't remember, that does not mean that he has not actually maybe discussed the full implication of non-A, non-B hepatitis with us.

But the simple answer is I don't remember. But as I said, that does not mean he did not discuss it.

Q. No, I understand that, doctor. But your impression -- or your evidence suggests that Professor Bloom's view as communicated to you was that non-A, non-B hepatitis was a fairly mild condition, not something to be too concerned about.

A. Well, I think he -- you know, the way he said in the vast majority of patients he's seen it was a mild condition, but because we did not know what the cause of it and there was no particular treatment, he taught us what our role would be, is to monitor, advise against any, you know, advice about alcohol, advise against any drug which could worsen the liver function tests, and whatever.Well, I think he -- you know, the way he said in the vast majority of patients he's seen it was a mild condition, but because we did not know what the cause of it and there was no particular treatment, he taught us what our role would be, is to monitor, advise against any, you know, advice about

alcohol, advise against any drug which could worsen the liver function tests, and whatever.

You know, there are certain things which sticks in your mind simply because you are involved with them and I was -- when I was an SHO and it was Saturday and it was not unusual, either Saturday or Christmas Day or whatever, it was, you know, not a normal working day, and I remember there was a patient with haemophilia who had deep jaundice and because I was the SHO I was looking after that patient as well and I remember Professor Bloom came on that day, particularly to see the patient because he was worried about the patient.

The thing about that patient when you look at the liver function test, you find that the jaundice was not really what we call a hepatocellular jaundice, it was what we call an obstructive jaundice. There is something blocking the drainage of the bile.

Now, I remember that case because when I looked at the medication I saw that the patient was on an anti-sickness, which is called Largactil and that is well known to cause obstructive jaundice and, like any of these things, when you have done something useful, you tend to stick into your mind. So I mentioned that to the registrar and he mentioned it

to Professor Bloom, and I think he said to the effect that all that is -- "I'm glad that is the case because I haven't seen such a type of jaundice in a patient who is not hepatitis B".

You know, these are glimpses which I could recall but, as to the rest of it, I'm afraid I cannot recall everything as what he said, but he used to convey to us in, you know, sort of -- I mean, he's not a person who actually was opinionated, he was very willing to change his opinion depending on what he had learned and he would convey to as trainees as what was the understanding of the time and he would not be a person who would take one position and will continue with that even when the evidence shows to the contrary.

Q. There's just one further description of non-A, non-B hepatitis, contemporaneous description, I wanted to ask you about. Again you would not have seen this document at the time, doctor. Soumik, it's WITN0282008.

This is an internal Department of Health memo, doctor. Again, it's in the material that has been generally provided to you but there's no reason to think you would ever have seen it at the time. It's September 1980. In the third paragraph, it says this:

"I must emphasise that 90 per cent of all post-transfusion (and blood-product infusion) hepatitis in the USA and elsewhere is caused by non-A, non-B hepatitis viruses which (unlike hepatitis B) cannot, at present, be detected by testing donor blood. This form of hepatitis can be rapidly fatal (particularly when acquired by patients with pre-existing liver disease) or can lead to progressive liver damage. It can also result in a chronic carrier state, thus increasing the 'pool' of these viruses in the community."

I just wanted to break that down and see to what extent you understood any of these matters in the early 1980s.

A. I did not -- sorry.

Q. I'll just do it bit by bit if that's all right. Were you aware in the early 1980s, so 1980 through to 1983/4, that 90 per cent of post-transfusion hepatitis, or the majority in any event, whatever the precise percentage, of post-transfusion hepatitis was caused by non-A, non-B hepatitis viruses?

A. I do not remember the non-A, non-B -- as I said, I was always intrigued why they call it non-A, non-B hepatitis and not non-A, non-B viral hepatitis. So this is maybe one of the few times where the word

"virus" is mentioned.

I knew that after hepatitis B was eliminated from the blood transfusion and concentrates, the vast majority of patients which showed the abnormal liver function test is what this called non-A, non-B hepatitis. But that is after the elimination of the hepatitis B, yes, so it will be in the 80s.

Q. Did you know, did you understand, that non-A, non-B hepatitis could be rapidly fatal?

A. No, I haven't -- I haven't seen that. I'm sure there would have been reports about it but I haven't seen that.

And just to reflect on the small practice we had in Swansea, I've seen only two cases with hepatitis C who actually developed liver cirrhosis and was -- probably participated in their death. One is a patient with hepatitis C and HIV. Unfortunately, he was severely disabled, even though he lived to his 50s. His mother found it very difficult to persuade him to have any of the treatment for either. He did have some treatment for HIV but he would not continue with that.

The other patient is what I referred to you in my statement who -- we knew that he had a concentrate, because of the teeth extraction, and then he wouldn't

attend the haematology out-patient clinic, and the next thing I knew is that he was under my colleague, who is a hepatologist, with liver cirrhosis, and he died of liver cirrhosis.

So, you know, as far as my own experience, I haven't seen that, but -- because I haven't seen enough of them, but non-A, non-B hepatitis in the 80s were by the vast majority of the haematologist. And not just in the UK, worldwide. I mean, there were the publication which shows that if you do a liver biopsy and you could find chronic persistent hepatitis, chronic active hepatitis, cirrhosis, even in some of the children from Lilleyman, who was -- used to work in Cardiff.

But I think the vast majority of us thought that non-A, non-B hepatitis was not a big issue.

Q. But did you know as a matter of fact, were you aware that it could, as put here, lead to progressive liver damage?

A. Yes. I mean, we knew that it could lead to progressive liver damage, but if you ask me when did you actually become aware of that, that I cannot tell you. I cannot tell you as when -- I knew that even in the 80s we used to send those patients for ultrasounds and that is -- really was -- and we would examine

every single patient clinically for any signs of cirrhosis, including spider naevi, including ascites, including whatever signs we knew of palmar erythema. But I really did not know that -- you know, sort of, there are quite a percentage of them who would develop progressive liver disease and could die of cirrhosis or hepatocellular carcinoma.

Q. You have explained that in terms of the general approach to the treatment of patients with bleeding disorders, you relied upon and you deferred to the advice of Professor Bloom for the reasons you have given, that you understood him to be more well informed than you were. Is the same true in relation to hepatitis, that you would have regarded Professor Bloom as more knowledgeable than yourself or was that not the case?

A. No, I think we were blessed in Swansea in that shortly after I was appointed, my colleague Jerry Kingham was appointed I think a year or two later, and he made it very clear he was interested in hepatology as well as gastroenterology. And later on, in 2006, we had a superb colleague as well appointed who was -- main interest in hepatology.

So I think I, you know, sort of, was so fortunate really in that in Swansea, all the time

I worked in Swansea, we had a good hepatologist who we would be able to refer patients to. And I must say, I mean, for any liver condition, I would have informed Arthur that such a patient would, you know, may be experiencing whatever, but I would have to referred to the hepatologist.

Q. Can you recall in what year was Dr Kingham appointed? Was that -- you said when you were appointed -- was that '82 or are you talking about '85?

A. I think he was appointed in '84, '83 or '84. I can't -- I mean, he was appointed soon after me.

Q. Do you recall any discussions with him in the early or mid-80s about the nature of non-A, non-B hepatitis?

A. Now, interestingly, one thing which springs to my mind, we were in the coffee room and -- but don't ask me on the year because I won't be able to tell you -- and he said to me, "Saad, I've been to this international meeting, did you know that all your patients who had received concentrate had non-A, non-B hepatitis?" I said, "Yes, I knew about that. What we are going to do about them, Jerry?" And he said, "I don't know."

Q. What, if any, information did you personally provide to your patients in the early or mid-80s about the risks of hepatitis from treatment with blood products?

A. As I said before, the risk of treatment with hepatitis you would discuss with the patient when you offer the treatment. But I'll tell you what would happen in the out-patient clinic. When we started regular out-patient clinic and, for that matter, even before we start regular out-patient clinic, what happened in when haemophiliacs would come in, the usual thing is you listen to the patient, what are the issues and whatever, you examine their joint, and then you go through with them with the investigation.

So you start with the full blood count and you go through the liver function test and you say, oh, by the way your liver function test showed that your enzymes, liver enzymes, are raised. What does that mean, doctor? Well, it means that there is an inflammation in the liver, probably related to the treatment but we do not really know how that is going to change, whether it is ever going to change but we'll advise you, you know, to be careful with alcohol and, you know, sort of in terms of what medication you are on to see any of that.

That is the sort of conversation and so many of them would say: Is there any treatment for it? No, there isn't any treatment that we know of, simply because we do not know what is causing it.

That would be, if you like, the classical conversation with a haemophiliac and, for that matter, for any abnormality. So if the patient had anaemia you would talk about, look, you've got anaemia and the picture is of iron deficiency, probably because you have lost blood in the urine or whatever. These are the sort of information. So the patient would know what their result would have shown and we would have explained to them what we think of it, gave them the chance to ask any questions. Very often, when you say that "Would you like me to ask our liver specialist to have a look", so many of them would say, yes, please, others would say, well, if they haven't got anything to offer me I would rather leave that for the time being. So that sort of conversation.

Q. I understand what you say about conversations in relation to liver function abnormalities, but did you, in the early or mid-'80s, have conversations with your patients in which you would tell them that there was a risk of them developing non-A, non-B hepatitis or developing chronic liver disease, as a result of the blood products that they were receiving?

A. Well, by definition they would have had non-A, non-B hepatitis, because they had concentrates. If they have not had concentrate and if I am to embark on

concentrate, I would have explained that, look, there is a risk that, even though we know that hepatitis B is not transmitted any more, that there is a risk of your liver showing an abnormality, we call it non-A, non-B hepatitis.

But if you ask me have you told them that, look, this could progress to cirrhosis or this could progress to cancer, no. If they had -- if you turn the question the other way around and if they say, "Could that mean that I could die of it", well, I don't know, you could if it progresses but because we are monitoring you we will be checking how you are progressing. Now, I'm saying that not as to remind me of a particular conversation but I'm saying that because that is the attitude I would have taken with a patient. I've always said to my patients, look, the one thing I do not do here is speculate. I'll tell you the facts as I know them, but don't you ask me to speculate because I will not be able to speculate unless I know, you know, sort of the high percentage of certain things happening.

MS RICHARDS: Sir, I note the time. Is that a convenient point for lunch?

SIR BRIAN LANGSTAFF: Well, it is. Just before we break for lunch, can I mention one thing. We have been

exploring a little, for obvious reasons, what Professor Bloom, Dr Bloom as he was in the 1970s, may have thought of the risks of non-A, non-B hepatitis and you've addressed the general risks by reference to a couple of documents. But I do have a note, and I am addressing this really to you and for those who may be listening, because the doctor won't himself have come across this but I have a note of a letter which Dr Bloom wrote on 10 February 1975. That's a date which may -- and I shall have to place the significance of this in due course, no doubt with the assistance of any submissions -- that date is some three years after the test for hepatitis B was first introduced. It is about six months after Prince wrote in The Lancet identifying that more than 70 per cent of post-transfusion hepatitis was caused by something which wasn't hepatitis B, therefore virus or viruses non-A, non-B. What he said to a GP concerning a patient of his, whom I certainly shan't mention, the reference is witness W0047002, he said a small percentage of these freeze-dried preparations -- plainly he is talking about concentrate -- contain, unavoidably, the virus of serum hepatitis and therefore potentially dangerous -- that's the word he uses, "dangerous" -- to the patient, his relatives,

et cetera.

That's a note which I came across and it struck me for three reasons. First, that he is describing serum hepatitis which could be and may well be in context non-A, non-B, as well as hepatitis B. He described it as "potentially dangerous", and he is describing the possibility that it may infect others than patient, ie it is transmissible, potentially. Since we have been talking about that I thought it right to indicate what is at least part of the state of knowledge -- the state of information, I won't say knowledge -- which I have and I will have to place that in due course.

MS RICHARDS: Yes, which we looked at --

A. Can I make a comment on that?

Q. Yes, of course, doctor.

A. I think -- you know, sir, from what you have read to me now, I think when he says a small percentage would have serum hepatitis, I -- you correct me if you think I'm wrong -- I think he was referring to perhaps the concentrates which escaped the elimination of hepatitis B.

SIR BRIAN LANGSTAFF: You may well be right, but the problem is that he can't help us with what he meant. It has to be interpreted in the light of the context,

and he uses the expression "serum hepatitis", which is capable of covering, and almost certainly did, before the identification of hepatitis B, cover both B and any other virus which was causing hepatitis. So I just raise it. I don't want to debate it here. It's for other times -- thank you.

A. If you permit me, I just want to say one word, because when he says a small percentage, he must have known that, in fact, the vast majority of patients who haven't got hepatitis B would have these abnormalities. When he says a small percentage, in my mind, and I think he -- even in the 80s we will say "Look" -- to the patient -- "hepatitis B is very unlikely, but there is a small risk that, you know, some of these may actually -- these concentrates may convey it."

The reason why I'm mentioning that I think he is referring to hepatitis B, the words "small percentage", because if he was referring to the hepatitis as we know it now, non-A, non-B, it certainly was not a small percentage.

SIR BRIAN LANGSTAFF: Thank you, doctor.

I will have to consider that in due course. But for the moment let us take a break for lunch. We will be back, please, at 2.05. So 2.05.

Again, doctor, don't talk to anyone about your evidence, but I hope you have a pleasant lunch where you are and look forward to seeing you again at 2.05.

A. Thank you, sir. I hope you will have a pleasant lunch. I am having a packed one. I do not know whether you are having a packed one as well.

(1.07 pm)

(Luncheon Adjournment)

(2.05 pm)

(Technical issues - no audio feed)

SIR BRIAN LANGSTAFF: The reason for doing it is this, that not only are your words being heard, and online, if they can be heard, but they are also being transcribed. I am being told there is no sound.

If that's right and people can't hear what you have to say, and that's obviously the whole point of this, and also it can't be transcribed. So for both reasons we will just take a break at and see what is happening and see if -- ah, we've got it back.

MS RICHARDS: Yes, I understand the issue is now resolved.

SIR BRIAN LANGSTAFF: The position is resolved. Thank you very much.

Do you want to ask that question again? I am sorry to have to ask you to go through that again.

MS RICHARDS: Yes.

What I'm trying to explore with you, doctor, is the extent to which you advised patients of the risks involved in the use of concentrates, specifically the risk that concentrates might cause liver disease.

A. Okay. I'll start right from the beginning because I'm not very sure whether you heard me, Ms Richards, or not.

SIR BRIAN LANGSTAFF: Assume we didn't hear anything, please, and start again.

A. As I said before, the risk of the treatment the patient likely or could have would have been explained with the first consultation, when the treatment was explained. And I certainly did that when I had a new patient, I certainly did that when a patient who had not had treatment before needed to have concentrate.

But what I did is, as I explained before lunch, when a patient would come to see me we would go through -- after examining the patient, we would go through the results of the patient. And if -- the result, I'll say that, "Your blood count is okay", or, "By the way, we did a liver test, and that showed an increased enzymes", and if they ask me, "What does that mean?"

"That is probably related to the treatment you had."

"What does that mean, doctor?"

"I really do not know what is going to come out of it, but if you like, I could send you to the liver doctor."

"Would he have any treatment to offer me?"

"Not at the moment. We do not have any treatment because we do not know the cause of it."

But I would not have held any information from the patient. I have not had any patient who would turn to me and say, "By the way, if you think that is causing the disturbance in my liver test, I'd rather stop it". I've never had that. And I have never had a patient who would say, "Would there be a possibility to switching to another treatment and seeing what happens?" I've never had that.

MS RICHARDS: So is this right, doctor, that because in the period in the early to mid-1980s you were not seeing new patients, you were not seeing patients being treated for the first time, your assumption is that they would have -- any conversation about the risks of treatment would have taken place beforehand, whether with Dr Khurshid, Professor Bloom or someone else.

A. Yes, I think -- you know, sort of, when you see a patient for the first time, it is the usual practice

to explain to the patient what you've got to offer to them. And it is usual to explain what is the known side effect of what you have offered to them. And you tried to explain that to the best you can.

Q. Did you ever, in the course of the 1980s, before the test for hepatitis C was available, diagnose non-A, non-B hepatitis in your patients?

A. Oh, yes. I mean, some of the patients who were referred from other centres were referred, and they already with the first consultation they said that we know we've got this condition called non-A, non-B hepatitis. The patients who I have and they have this disturbed liver function test has said, "What does that mean?"

"Well, we've got a name for it. They call it non-A, non-B hepatitis."

"But what does that mean, doctor?"

Well, to be honest with you, I don't know."

"Is it a virus, is it any --"

"I don't know. Until we know the answer to it, I don't know what the answer to that."

Q. Was it your practice to record discussions about risks or discussions about non-A, non-B hepatitis in the patient's medical records?

A. If I am to see the patient for the first time

I certainly do that. And I'm saying that because that is my practice with patients, whether they are haemophiliac -- as I said, the vast majority of my patients were patient with the blood cancers. And I would document, maybe in bullet points, what has been discussed with the patient. It is usual to -- that is -- usually happens with the first consultation or when something new crop up. For example, if you want to offer a treatment and whatever, you would probably go back and talk about the reason why you are offering treatment and so on and so forth.

That usually would be either in the notes in the letter or both. That would be the usual thing. If you ask me have you done it with every single case, I wouldn't be able to answer yes or no unless I see the notes.

Q. Can I then move on to the question of AIDS.

You have said in your statement that you are not sure exactly when you came to know about the association between blood and blood products and AIDS, but you have recorded in your statement that the Centers for Disease Control in Atlanta published its first report about AIDS in haemophiliacs soon after you started your post as a consultant haematologist in Swansea in 1982. And, indeed, we know that

publication was July 1982. Does that -- sorry, carry on.

A. Sorry. Keep going.

Q. Does that mean that at some point soon after you started your post you became aware of the CDC announcement?

A. I wish I know when, because I honestly cannot tell you when I knew. But at some stage I knew about the CDC announcement, about their report, and I knew, for example, in -- I think it was in 1983 I've heard about the patient with AIDS in Cardiff. So I came to know about the CDC report at some stage. But with all honesty I cannot tell you exactly when, which year.

Q. You told us in your statement, and you said earlier today, that in terms of the publications you read, they included the New England Journal of Medicine.

A. Correct.

Q. I won't go to the detail of all the various articles but does it follow it's likely that you would have read, for example, the articles and communications in the January 1983 edition in which there were various reports and discussions about AIDS?

A. I probably would have. If you particularly show me what you have in mind and I will be able to tell you whether that's something I know or it's something new

to me.

Q. We'll look at just one. There are a number of examples but we'll just look at one.

It's PRSE0002410, please.

This is January 13, 1983, in the New England Journal of Medicine, "AIDS and preventative treatment in hemophilia".

A. This is Jane Desforges --

Q. That's right. Do you think you would have seen that at the time?

A. I've seen it but I tell you it did not impress me then. Now, looking at it retrospectively now, it was very, you know, far-thinking article, but it did not impress me at the time. And if you permit me I'll tell you why.

Q. Yes.

A. Because I think you probably know that -- the New England Journal of Medicine had a habit of -- the main editorial usually discusses or discussed the couple of publications which are important in that journal. Now, the two publications which came with this article, I think one is Liderman and one is McNorth or whatever, both publications what they talk about, they talk about a change in the lymphocyte subsets in patients with haemophilia who had

concentrates. Okay? But if you look at what their results shows, in fact neither group of patients had any evidence of AIDS, and even the T4 lymphocytes were not below normal but was lower than the patient who did not have the concentrates.

And if you go back to the last paragraph of this article, please.

Q. Second page, please, Soumik.

Zoom in on the left hand column, bottom of the page.

A. If you can enlarge the last paragraph, let's read this paragraph together:

"The fact that haemophiliacs are at risk for AIDS is becoming clear. If the use of cryoprecipitate will minimise this risk, the current home-infusion programme needs to be revised. The studies reported in this issue demonstrate in vitro abnormalities of immuno-regulation, but the numbers are too small for [definite] comparison of the risks of different modes of treatment."

SIR BRIAN LANGSTAFF: "Definitive", I think.

A. "Definitive".

"Unfortunately, the data or consistent with a greater potential ... [whatever]. Physicians involved in the care of haemophiliacs must now be

alert to this risk. Preventing the complications of the present treatment may have to take precedence ..."

If you go to the paragraph before that, it is -- the one before it before the last paragraph.

SIR BRIAN LANGSTAFF: Top of the page, I think.

MS RICHARDS: That's the one.

SIR BRIAN LANGSTAFF: "This issue of the Journal contains", I think is what you are looking for?

A. No, "Ease in obtaining the commercially ..."

"It would be difficult to design a home-infusion programme with a cryoprecipitate therapy since the material must be stored in the frozen state. The present programme has been extremely successful and would be given up by physicians and patients only with great reluctance. Yet it is time to consider doing so, even though we may not have enough evidence to demand such a radical change."

So that was suggested with this wording when there was no credible alternative and the author clearly said, you know, sort of cryoprecipitate is going to be a difficult thing to do when there was no credible alternative to concentrate.

The other thing is, of course, if, let's say, theoretically that we would do that, you know, changing to cryoprecipitate that means the BPL would

have to stop providing us with NHS concentrate and the logistics of the process of changing to cryoprecipitate is immense. I already hinted to the difficulty of giving cryoprecipitate as home treatment, and I refer to the patient which described to me that cryoprecipitate dominated her life and, in fact, at the end of the day, cryoprecipitate unfortunately did not deliver the goods.

So that is the reason why, you know, sort of most of us were not impressed by the suggestions. 40 years later, of course, her prediction and other people's prediction proved to be correct but, at the same time, the World Federation of Haemophilia, the Haemophilia Society, what is called the equivalent of The Haemophilia Society in the US, they all came to the same conclusion that you could not stop using concentrates.

Then you talk to people, you know, sort of in big treatment centres, Cardiff, Manchester, Royal Free, and you mention to them, you know, would we be going to back to cryoprecipitate? Oh, you must be joking, it's impossible.

So that is the reason why cryoprecipitate was not a credible alternative. If there was a credible alternative, I think many people would have thought

again, you know, than continuing with the programme. But there was no credible alternative.

MS RICHARDS: Can we just look at this article again, the last paragraph. There are two parts to this paragraph. You've alighted upon the second part of it, which is the suggestion that there may need to be revisiting the current home infusion programme and the greater use of cryoprecipitate, but the first part of it is the statement that the fact that haemophiliacs are at risk for AIDS is becoming clear. Did you take issue in January 1983, or whenever you became aware of it in 1983, with that statement, and did you understand by early 1983 that there was reason to consider that the haemophiliacs were at risk of AIDS?

A. In the early 1983, and I think I've sent you so many references, and fortunately you have already had them because you send me back the reference numbers, you know, there were two arguments going on at the same time. One argument is saying: look, the issues of AIDS in haemophilia is not related to an infective agent, it's related to the exposure to the antigen that is the foreign protein which comes with the Factor VIII from another person; and there is a group which said, look, this is going to be very much like hepatitis B. You know, you really do not know -- you

did not know then as what is credible.

By 1983/84, the argument that an infective agent is more likely became more and more acceptable until the agent was identified as the retrovirus HTLV-III, initially. So there were two arguments going on at the same time but I think I sense what you want to ask me. Did you share that with your patient, Saad Al-Ismail? Well, you may know that the haemophiliacs, unlike other groups of chronic illnesses, they were truly informed as to what is happening around them in the world and I have yet to have had a patient who would come to me and say, well, I've heard about this, I want to stop using anything which may, you know, sort of, give me an infection.

I would have happily discussed that with them and thought what are the alternatives, the alternative is cryoprecipitate, but for the patients who were receiving cryoprecipitate, most of them have to and did having it in hospital, and for those who have to have it at home it was a big issue, and I think one of the witnesses which you sent me the statement for said that he spent most of his life in hospital.

I have not watched the programme World in Action but I saw it since, when you actually included it in one of your evidences, and I managed to listen to it

on the YouTube, and I remember one thing which Professor Bloom said to me, which I didn't understand at the time. He said to me, you know, the haemophiliacs are aware that they are taking risks, and I thought he was referring to the hepatitis B and I did not understand what he meant really until I watched that programme and I got the references for the transcript, which you've kindly sent, which I've read after watching the programme, which were Mr Robinson, I think, said that we knew of the risk and Mrs Robinson said -- I'm not quoting her exactly -- but she said we did not take a chance or something with our children's lives, but we knew of the risk. I think the programme was about Hemofil and she said Hemofil was a calculated risk.

The reason why I went into such a long answer is to say that I really do believe that haemophiliacs knew the risk and my understanding that with every single concentrate there was, you know, sort of, the drug information leaflet.

I was assured -- I haven't seen one, but I was assured by Professor Bloom that in each one of them a reference was made, for example, to the hepatitis, not to the AIDS. So I think, you know, sort of, a long answer to your question: did I take action on

the first sentence? No, because there was a counter-argument and there was no credible preference. Did I discuss it with the patient? Well, none of the patients certainly raised the issue with me and if I am to raise the issue I should really have a clear view as which argument is going to be the more credible argument. I think the argument of an infective agent would have been acted on if there was a credible alternative to cryoprecipitate much earlier.

Q. As I understand the answer to the question that you correctly anticipated I was going to ask you, you didn't yourself tell patients in 1983/1984 of the risk of AIDS. As I understand your answer, that's for potentially two reasons: firstly, you're saying that in early 1983 at least, I think you're saying that there was a credible alternative explanation and, secondly, you're saying that you assumed that patients would have the information themselves.

Is that right?

A. The third one is that there wasn't a credible alternative, for treatment.

Q. What's the basis for your assumption that patients in 1983 and 1984 understood the risk of AIDS from the use of blood products?

A. Well, I didn't understand fully the risk of AIDS from use of blood and blood products, simply because there were too many arguments, one pointing in one direction and one pointing in the other, and you asked me whether I've read The Lancet and I said I've read The Lancet in the library. There were so many articles, leading articles, in The Lancet to say, look, this AIDS issue is -- this reduced immunity in the haemophiliac is very much related to the concentrate -- to the antigens in the concentrate. There were other arguments saying, look, the AIDS in the haemophiliac is going to be different from the AIDS in the homosexuals and the drug abusers because there are certain mitigating issues in that population using nitrates and whatever, and that in the haemophiliacs the processes may have altered that.

There were so many arguments going at the time that it was very difficult to give an informed opinion to any patient as what I knew as for a fact then. When the virus was diagnosed and we had a test, it was much easier then to talk about it but it was too late. In fact, it was too late by 1982/83 as we learned later. But it was -- really to discuss something with a patient you have to be informed. We may be able to talk about variant CJD later on but when I call

a patient I give them the opportunity to sit down and talk about variant CJD, some of them said why did you tell us this if you do not know the answer to it? I explained, look, one of the reasons why I'm telling you is because of the public health issues whatever. The point is you really are only be able to discuss with a patient an issue if you really have made a firm opinion as what you want to advise the patient.

Q. Dr Al-Ismail, if you didn't fully understand the risk of AIDS, what's the basis for your assumption that your patients were sufficiently well informed?

A. Well, the patients were informed because of the meeting of The Haemophilia Society. The fact that Professor Bloom called the patients even from Swansea and their relatives to go to a meeting in Cardiff, I think he probably had more than one meeting, the newsletters which The Haemophilia Society distributed, there were so many things distributed. I'm not saying that they were better informed than me. What I am saying, for me to actually preach to a patient something, I really need to understand fully what are the evidences for it. Is it truly an infective agent? If it is an infective agent, like so many people have said, is it going to be like the hepatitis B virus or is it going to be like the non-A, non-B hepatitis?

There were so many issues I did not know and that is not just me. I think the vast majority of people, unless they are strongly in one camp or another, have the same view. Some of the haemophiliac doctors their patients, look, it is definitely not an infective agent, the others told them it is. But I did not really know which argument was going to be the true argument or the true cause of AIDS.

Q. Did you ask Professor Bloom for his advice as to what patients should be told about the risk of AIDS?

A. I think we have talked about it. Professor Bloom had initially, prior to -- I think, the first death he had, if I remember right, was in August '83 prior to that he thought that the AIDS is not going to be a big issue in the haemophiliacs. Even in 1984, as you well know, when his survey of more than 100 haemophilia centres including UK and Europe he had 13,000 haemophiliacs who were treated and that is 1984. Only 11 of them showed the Acquired Immune Deficiency.

Now we know things that we did not know then. Now we know the incubation period of Acquired Immune Deficiency, of HIV, is a long one. Now we know that it is -- you know, sort of -- when the antibody test came in, we did not know what that antibody test meant until we had a chance to actually look for the

transcript of the virus. So that antibody was not a protective antibody.

There were so many issues that nobody knew, but you have asked me did I speak to Professor Bloom? I spoke to him about this many times, and his view is initially that we are not going to have -- we are not going to see the same problem as the -- in the homosexual population and the drug addict, we're going to see it in some of the patients, and he based his opinion on the survey that so many patients were treated, so many patients had HIV antibodies but so a few of them developed.

Then, unfortunately for all of us, when the disease started to progress, it was like a bushfire really. Everybody was so depressed when that happened.

Q. Can I ask you to look at --

SIR BRIAN LANGSTAFF: Just before we leave this, can I just ask you a couple of things that arise out of the questions you have been asked, doctor, if I may?

A. Please.

SIR BRIAN LANGSTAFF: As I understand it, your first reason for not telling patients about AIDS was there were two different arguments. There was a counter-argument to the argument that it was a virus

contained in the factor concentrate; have I understood that correctly?

A. You understood that correctly. But if a patient had asked me what -- "I've heard about this, doctor, what do you think", I would have presented both argument to them.

SIR BRIAN LANGSTAFF: You were taken to the very first sentence in that last paragraph:

"The fact that haemophiliacs are at risk for AIDS is becoming clear."

That's linked to concentrates. There's nothing in that sentence that talks about a virus, is there?

A. No.

SIR BRIAN LANGSTAFF: If it wasn't a virus, it was the factor concentrate, was it, that was creating the lack of immune reaction or the antigenic reaction which gave rise to AIDS, was it?

A. That's true.

SIR BRIAN LANGSTAFF: So whether it was the argument or the counter-argument as to what was the cause, there was, on both accounts, a risk of catching AIDS from having concentrate. Quite how you got it was unsure but there was a risk.

A. Yes.

SIR BRIAN LANGSTAFF: So in the light of that, was it

really an argument to say that you shouldn't say anything about the risks of using concentrate to your patients when both the argument and the counter-argument ended up at the same place, that it was the concentrate that was likely could give rise to AIDS?

A. With all respect, sir, I did not say that it's not right for -- to mention anything. What I was asked: would you have to explain the risk of AIDS to your patients? If I knew exactly what the risk of AIDS in a particular patient, I would have, but I did not know what would be the risk of AIDS in a particular patient --

SIR BRIAN LANGSTAFF: That was all that I was asking. I just wanted to clarify that. Thank you very much.

A. Pleasure.

MS RICHARDS: Could we have PRSE0002647, please.

Doctor, these are the notes of a meeting at which there was a discussion on AIDS chaired by Professor Bloom. It's not a meeting you attended. It's 24 January 1983 and it was a meeting between a number of clinicians and representatives of Immuno at a London airport hotel. If we could go to page 3 please, you'll see there's a heading, "Acquired Immunodeficiency Syndrome" -- bottom half of the page

please, Soumik -- and there's a description given, what's said to be a summary of the current position by Dr Craske.

Go down so we can see the bottom of the paragraph in full, please. Thanks.

So we can see in the penultimate paragraph it says:

"Some 800 people had been reported as suffering from AIDS, and there was a 45 per cent mortality."

Then there's an update about the position in relation to haemophiliacs and then a reference to other cases involving blood and blood product transmission, including platelets transfused in three cases, and specific reference to the case of a 20-month old child who had received several units including platelets and had developed a possible AIDS state. We refer to that elsewhere, doctor, as "the San Francisco baby case".

Go over the page, please. Look at the top half of the page. We can see there there's express reference to the length of the incubation period, it appears to be six months to two years. Reference to only one or two cases having been reported. Reference to possible precautions. There's then a discussion about articles in the New England Journal of Medicine

and a distinction between concentrates and cryoprecipitate and then comments on the possible nature of the transmissible agents, indicating that there may not be just one agent but a mixture, ie possibly a barrage of viruses.

Two questions for you, doctor, arising out of this. We know from this, we in fact know from other material as well, that Professor Bloom was aware of the case of the San Francisco baby case, the child transfused with platelets developing an AIDS state. Do you recall any discussions between you and Professor Bloom about that case and its significance?

A. No, but I recall what he has written in his report. That's his litigation report. And I recall very clearly that he said in his report -- I think he was in a meeting with The Haemophilia Society in 1983, only two months after his first patient died with AIDS, and in that report he said -- what was his wording? "I became more concerned about the possibility of ..."

I've written it here somewhere. He said ... he was more circumspect than previously -- that is in October 1983 -- than previously with regard to blood products and AIDS. So really by then he clearly started to believe in the -- more the theory that an

agent is probably responsible for the AIDS.

So I'm very aware of that report. But as I said, until the virus was identified, many of us really -- the argument shifted more and more toward an infective agent but it was only when the virus identified that it was convincing. And by the way, even when the virus was identified, so many papers appeared afterward saying that this is not the cause of AIDS, this is an opportunistic infection in patients who has got AIDS.

So you could see how the arguments we know sort of moved over the years. But if you ask me -- what was the date of this meeting?

Q. 24 January 1983.

A. Yes. So if you ask me has he shifted his opinion, yes. Have he conveyed that to me? I don't know when, but I certainly read it when he shared the report with me.

Q. Did he -- I think the answer to this is "no", from your earlier answer -- did he, whether following this meeting or otherwise, discuss with you the significance of the infection of the baby in California?

A. No, he did not.

Q. Would you agree -- and picking up on the chairs

question a few moments ago, looking at this discussion, there are obviously matters which are not yet known but there's no suggestion here that there's anything other than concentrates and a transmissible agent that are being put forward as the likely causal connection?

A. Yes, but this is, as I said, one argument. There were a plethora of publications talking about an alternative arguments. And the difficulty for people who really was -- I think even people in the haemophilia world, the people in the Royal Free and the like, initially they did not believe an infective agent was responsible until later on.

So I don't think Professor Bloom was alone in that thought really. I think -- so if you are talking about people like him, he probably would have intermingled with people in the USA, in Europe and whatever, and he was on regular correspondences with them.

He reminded me so many times that, "Look, in Germany they use more American concentrate than we use here but they haven't had a case of AIDS". So all this these things were happening. And he was a person who, as I said, was listening to all these views and -- and I said before, he wasn't an opinionated

man, he was quite happy to shift his opinion when the argument points him in one direction or another.

Q. What steps were taken at Swansea in response to the possibility that concentrates might cause AIDS in haemophiliacs?

A. Well, I don't know of any specific -- I mean, what happened is that we would -- became more adamant that mild haemophiliacs should not receive anything but cryoprecipitate or DDAVP. We became more adamant that, if it is all possible, children should be treated with the cryoprecipitate. Fortunately for me, as I said before, there were -- I did not have any new patients until the advent of the safe products came through.

So in terms of the current patients we had, the only thing we could do is really monitor them and look after them. But in terms of changing the practice of treatment, there were no change of practice, simply -- and we used as much NHS concentrate -- I've already said that before -- as we could get hold of. And when the heat treated product became available, we used that. But there was no other alternative, credible alternative, in the severe haemophiliacs and for home treatment.

So the short answer to your question, was there

any specific measures apart from, you know, sort of monitoring the patients more carefully? No. Apart from trying to answer any question which the patient, their mother or their family have raised? No. But we answered the questions according to what we have read in the literature.

Q. Could we have, please, HCDO0000517_001.

This is a letter dated 22 March 1983. It was sent to centre directors from Dr Craske, Dr Rizza and Professor Bloom. And you will see it asked for the reporting of possible cases of AIDS, and various papers are there referred to.

Do you know -- this would have been addressed to Dr Khurshid, as centre director, rather than you. Did you see this, as far as you can recall, at the time or are you unable to say?

A. I say that Dr Khurshid always would have told me what he received and what he's acted, and I think I found later on that he had some forms and he reported to the UKHCDO, Dr Craske or whatever, whatever they have asked him to report.

So I'm sure that Dr Khurshid would have told me that he -- that "You've got another set of forms which you have to fill", and about the patients. But, again, I do apologise for taking, you know, so long

because I could not remember in full, but that, I'm sure he would have discussed it, knowing what used to happen. You know, whenever he received anything, he always mentioned it to me.

Q. If we could have HCDO0000517_002, please.

This is a report, Dr Al-Ismail, from Dr Craske dated 1 March 1983. I'm not going to go through it in great detail. The Inquiry has looked at it on a number of occasions, or earlier versions of it.

If we just go very briefly to page 3 you will see the bottom half of the page says "Aetiology", and says several theories have been advanced --

A. Can I ask to "Aetiology":

"The effect of drugs such as amyl nitrate taken by homosexuals ... This is not a factor as the disease has been described in patients who do not use the drug."

Okay. So there are so many things which were going round the immuno-suppressive cytomegalovirus.

Sorry, carry on.

Q. We can see that -- my main question about this document, Dr Al-Ismail, is, do you think you would have seen this at the time? Is this one of the category of documents Dr Khurshid would have shared with you?

A. I can't remember seeing the document, but I think, knowing how we worked together, is that he would have talked to me about it or mentioned it to me. But I cannot remember seeing the document myself.
Q. Did you yourself report any suspected AIDS cases to Dr Khurshid or Professor Bloom in the course of 1983 or 1984?
A. No.
Q. You have --
A. I didn't see it.
Q. You have referred to "the Cardiff patient". What, if anything, can you recall Professor Bloom telling you, not about the individual patient or who they were, but about the fact that he had a patient under his care who had AIDS, a haemophiliac patient?
A. I don't know where I've heard it, but most probably because, you know, doctors in Cardiff and Swansea talked on a regular basis. I don't know whether he told us or somebody else told us. I don't know. But I do remember that, you know, sort of, if you like, the first hint that it is happening at our doorstep happened in 1983, but we didn't really know what -- what's going to happen after. Is it going to be the odd case for whatever reason? We didn't know. We really didn't know.

But I've heard about it, whether it was from Professor Bloom or talking to colleagues in Cardiff. We very often talked to each other for different reasons, and whether they have told me, I don't know, but I've heard about it, yes.
Q. Did Professor Bloom ever suggest to you that the cause of his patient's AIDS was something other than the treatment he had received with factor concentrates?
A. No, he didn't discuss that. He didn't discuss that with me. But if you ask me whether he would have -- he could have -- even if he discussed it, could have said that with me, I don't think he would. I think he would have said it's the concentrate.
Q. We know in December 1984 UKHCDO recommended a move to heat-treated product. Do you recall any discussions, whether with Dr Khurshid or Professor Bloom, about the move to heat-treated products?
A. I think as soon as the UKHCDO suggested that we move to heat-treated products, I think Arthur was, you know, sort of instrumental in making sure that all of us would have gone to heat-treated product as soon as they became available. And I think we started with Armour and then we added Cutter later on.
Q. What steps were taken to ask patients who were on home treatment, and who had supplies of unheated

concentrates in their home, to bring those back in. Were any such steps taken?
A. Yeah, I've asked that question to the MLSO, the biomedical scientist who was -- and I asked him what did we do, and he said, "I'm certain that we asked patients to bring what they've got and we exchanged it with each input."
Q. Do you recall any difficulties in obtaining sufficient supplies of heat-treated products?
A. No.
Q. Do you recall whether any of your patients were infected with HIV through the use of heat-treated products?
A. Yes.
Q. What can you tell us about that? Again, without identifying any patients.
A. Well, it was a patient who was on Armour product. And to be honest, we would probably not have known about the cause until, I think, the Armour product was identified, because that batch, one of the donors was an HIV -- later developed HIV and AIDS, and he had donated. Then we had -- we had to follow all the patients who received that products, and sure enough one of them converted on that product.
MS RICHARDS: Could we have on screen HCDO0000132_039,

please.
Sir, I understand there's a problem with the external broadcast and so I'm being asked by RTS if we can have a break so they can resolve that problem.
SIR BRIAN LANGSTAFF: Yes. I just had that message myself.
So I'm sorry to stop you in mid-flow, Professor, it has happened twice this afternoon, but I hope we will have better luck a bit later on. We will take a break now. We normally have a break in the afternoon. We will have a break for about half-an-hour. So we will do that now and come back at 3.30. It gives us all a chance to have a cup of tea and for our broadcaster to resolve what the problems are.
A. Thank you.
(3.00 pm)
(A short break)
(3.45 pm)
SIR BRIAN LANGSTAFF: Right.
MS RICHARDS: Could we have the document that we were going to go to before we broke, HCDO0000132_039.
We can see that this is a letter from you, dated 18 December 1986. I'm not going to ask you about the specific patient, doctor. But it refers to a patient

having been exposed to an Elstree Batch, HL3186, in September 1984, and then you say this:

"Three of our haemophiliacs who were recipients of that batch seroconverted to HIV Antibody positive ..."

Then you refer to the seroconversion in one of them occurring between June 1985 and March 1986 and then you wonder if the particular patient about whom you are writing represents a another delayed seroconversion after exposure to that particular batch or possibly some other treatment he had.

Doctor, the first question is this: do we correctly understand from this letter that three, possibly four, of your patients seroconverted to HIV following receipt of this particular infected batch, HL3186?

We can't hear you, doctor. Hold on a second. We can see that you are speaking, but we can't hear you.

A. Can you hear me now?

Q. We can. Did you hear my question?

A. Yes, I heard your question very well. Do you want me to tell you a bit about this batch?

Q. About the batch, yes, not the specific patients, but the batch, please.

A. So this is a batch which actually was prepared in Wessex region, 7,000 donations and we were alerted to it by the head of Blood Transfusion Service there and that, in one of the patients who donated then developed AIDS. Now, unfortunately -- well, the batch was distributed in different places but seven of the haemophiliac in Wales got infected with this particular batch, and you'd find that in the report of Professor Bloom actually.

So that is the Elstree Batch HL3186, and you've kindly sent me a couple of other Elstree documents, I think, last week and you see they carry different numbers. So would it be in order for me to actually tell you that all these documents refer to the same patient? I'll give you the number of the documents.

So the first one is HCDO0000348_005. You find that is the letter from Dr Rizza to me, dated 11 December, asking me the question is: how come that we're having report of seroconversion in 1986 when we did not see that. Do you want me to repeat that number?

Q. I think we have it.

A. So that is the letter from Dr Rizza to me saying we need to know how come that this patient was not reported before all of a sudden appeared as being

reported to us. Can I give you -- about the same patient you have sent me two other documents and I've tied them together. Can I give you these, please?

So the first one is a letter from Dr Khurshid to Professor Bloom, the number, I'll spell it phonetically, Charlie Victor Hotel Bravo 0000003_65.

Q. It will be _065, I think. Could you just repeat that number please?

A. Charlie Victor Hotel Bravo 0000003_065.

So the only difference is that, I think the secretary there on our part got the year of birth wrong, '75. It should be '76, but you could check the particular of the patient, and I've checked it through another document on the same. So that is the document which Dr Khurshid sent to Professor Bloom saying, would it be possible to see this patient who received HL3186, and Dr Khurshid had a meeting with the parents but he thought that Professor Bloom would need to have a meeting with them. This is an example of how we collaborated with Cardiff.

The other number is Professor Bloom's response, which is Charlie Victor Hotel Bravo, again, 0000003_064. That is Professor Bloom's response to Dr Khurshid. So that is the same patient which Dr Rizza has written to me, asking: how come that

we're having this report here, we thought that you're using heat treatment?

There is an issue with the frequency of testing in this patient, in that the patient was -- even though we saw the patient, you know, sort of, maybe once a year or twice a year in Cardiff, the patient's residence was [redacted] so ...

Q. Forgive me --

SIR BRIAN LANGSTAFF: Just stop there.

MS RICHARDS: Dr Al-Ismail, I'm keen not to get into a discussion of the particular circumstances of particular patients.

SIR BRIAN LANGSTAFF: Can we just remove that from the record, please.

A. I apologise.

SIR BRIAN LANGSTAFF: Don't worry. We will make sure you don't say anything untoward.

A. Yes. That patient was not living in our area so we would not test him as frequently as we would test our patients. So that is the reason for the delay, I don't know when he converted, but according to us the tests we did in 1976 show that he converted. So that was the recipient of that particular Elstree Batch. So all these documents tie together.

MS RICHARDS: Could we just go back to HCDO0000132_039,

please, Soumik. The point I just wanted to clarify with you, Dr Al-Ismail, is this: the batch in question, HL3106, which seems from this letter to have resulted in three or possibly four of your patients, or of the local patients, sero-converting to HIV, this is a batch that was, as I understand it, supplied in August or September 1984 for use by the hospitals.

A. Yes.

Q. I think you made a point earlier in your evidence, doctor, you suggested that many seroconversions would have taken place in the early part of the 1980s, but a number of your patients were infected at a relatively late stage through the exposure to this particular batch; is that right?

A. Yes.

Q. This is obviously a communication that you're having with Dr Rizza, presumably in his capacity as maintaining the records at the Oxford Haemophilia Centre, nationally, of patients?

A. Yes.

Q. Did you tell your patients that you were providing information on a named basis, so not an anonymised basis, about their HIV status to Oxford?

A. Yes. We told the patients when the tests became positive that we would be sharing -- the HTLV test was

unlike any other test we did on haemophiliacs. There was quite a stringent way of doing it, really, in that we could not do it on the patient unless we had actually counselled the patient and very often we asked a patient if they want to bring anybody with them before we do the test. Then we do the test and when we convey the results, we also do it in one-to-one basis, and we tell the patient that -- we ask the patient that we need to inform their partner, wife and whatever, if it is a child then we would tell the guardian of the child, and our attitude then was not to tell the child because of the stigma, and the so many mishaps and stories you've heard about children inadvertently telling their friends in school and then being picked on, and some of the families they had graffiti written on the doors and whatever. We've heard the stories, didn't occur in our area.

So the point I was making is that the testing telling the patient and asking the patient if they don't mind it's important to share the information with their GP, I didn't have any patient who refused that and also telling them that we would be sharing the information with the UKHCDO because they will be monitoring the issue on the UK basis.

That is what used to be happening in terms of

the HTLV-III. So I don't think I remember a situation whereby we actually had to do it so regimentally as we did it in HTLV-III, simply because there was no treatment. We did not know what it meant in terms of the outcome. Much more importantly, there was such an awful social stigma about HTLV-III and the way it could be transmitted.

So all these sensitive issues, really, we -- needed to be handled very carefully.

Q. Could we have a look next at ARMO0000574, please Soumik. This is a letter that you wrote in August 1986 to Dr Christie of Armour Pharmaceutical Company and it's headed "Heat Treated Factorate Batch Y69402":

"I am writing to update you on the HTLVIII status on patients who had received the above batch of Factorate."

You refer to an earlier letter, and then you provide information about five patients. We're not quite clear what the redacted passage bits are but it doesn't look like you were providing names but you were providing information about individual patients.

Is this the heat-treated batch from which one of your patients was infected?

A. Yes.

Q. Although this information doesn't appear to contain names, did you tell your patients that you were providing any information about them to Armour?

A. As far as I remember, whenever we see a patient or guardians we will discuss saying that, you know, we received this information about an Armour product, where one of the donors, I believe, actually developed AIDS and whatever, and we will be -- we have been asked to provide information to -- now that is how I remember it. Whether we documented it or not, I don't know, but most probably we did. But that is as far as I can tell you.

Q. Then there's a follow-up letter, ARMO0000573, please, Soumik. We can see it's from Armour to you, dated 22 August 1986. It refers to there having been a visit and then it says that:

"... we have been asked [that's 'we', Armour] by the DHSS to follow up the progress and history of all other patients who were sero-negative at the time this batch was administered to them."

Then it is said that a particular interest is one of your patients, and continues:

"It would be most valuable to check with you, in strict confidence, the pattern of previous treatment with heat-treated and non-heat-treated Factor VIII

concentrates. Perhaps this would be best achieved during a visit, if you feel able to disclose this information to me."

There's some later reference to a visit being arranged. Can you recall whether you provided further information along these lines to Armour?

A. Well, I wouldn't -- I mean, as I said in my statement, I'm not -- that's not just in haemophilia. You get visited by different representatives and some of them will try to find out what I felt about their other product, or anything.

I was very careful and I made it very clear to a representative that I will be discussing their particular product. But in this situation there was, I believe, an issue in the sense that, in one of the meetings which I wasn't party of, it was said that haemophiliacs in Swansea converted on a heat-treated product. In fact, what they were referring to was the patient we were discussing a minute ago, the patient with the Elstree Batch.

I was a bit annoyed, and I shared that with Arthur at the time, saying if the UKHCDO was to get their fact right, then they really have to not listen to second-hand information, either they write to you or they write to me. But the answer to your question,

would I have discussed with Dr Christie and -- I apologise for him if he is to listen to this, because in my statement I referred to him as "she", because I couldn't remember who was Dr Christie -- I would have, told Dr Christie whether in a -- that patient had received this product but I would not have said, you know, sort of -- I may have said look if that patient reported in the UKHCDO did not receive your product but may have received other product, I may have said that but I would not have given full details.

Q. Can I then move on to the arrangements that were made for testing patients for HTLV-III. You have touched --

SIR BRIAN LANGSTAFF: Can I just be clear: the Elstree Batch given the date that it was administered in September 1984 was almost certainly not heat-treated; am I right?

A. Oh, yes, it wasn't heat-treated.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: Moving to the arrangements that were made for the testing of patients for HTLV-III, as I understand your answers a few moments ago, patients were invited to attend the hospital, were they, to give a sample for testing?

A. No, they were invited to come and talk about the testing before they gave a sample and I think you may find, because I blanked the names and did not keep the -- you will find in that copy of the letter, which is -- I think is the same document, which is the returns one, in one of the pages you'd find the testing on the patients in 1976, maybe.

Q. 1986.

A. Yes. You would find that some of them did not attend the appointment. So they were given appointments and the appointment was really to discuss the tests and the significance of the test and the importance of having the test. None of the patients refused the test, but we explained that, depending on the result, we have another meeting and, as soon as the results came back, that meeting was arranged and, I think I probably would be right in saying, most of the patients when they got the phone call to come to the meeting, they sensed what to expect, particularly when they were asked if they could bring their partner with them, if they liked. Some of them did, some of them didn't but it was so important that, you know, sort of to explain to them the mode of transmission. If you want to ask me about that later on.

But, again, I do apologise for the long answer

but the point is the appointment is not just for the test, the appointment is for a meeting and the test.

Q. Is this correct, the patients provided a sample, it was sent off for testing and then when the result came back and you notified patients that the result had come back, was news of the positive result told to them by you or by a nurse or by someone else?

A. No, definitely by the consultant, either me or my colleague Dr Beddall, all that information, because there were so many questions that were asked and had to be discussed. The hepatitis C was different that the results were conveyed by the nurse to the patient, but the HIV was definitely by the consultant.

Q. Your statement tells us that six adults with severe haemophilia A were HIV positive and two children with severe haemophilia A were HIV positive.

A. Yes.

Q. No patient who had mild or moderate haemophilia seroconverted to HIV and no patient with von Willebrand's seroconverted to HIV; is that correct?

A. True. Even the patient who had used all these units of cryoprecipitate, she was having regular testing and even the year she unfortunately died after the accident, she was seronegative for HIV.

Q. Do you recall over what time period roughly this process of speaking to patients, testing them and notifying them of their results took place?

A. Well, given the -- I mean, if you just give me a second, please, because I want to give you more details because I summarised them.

(Pause)

Okay, so of the patients who were tested in Swansea, the first test started in December '84. All the patients except the ones which were not living in our area they were all positive in '84 or '85. The only patient who we tested in '86, as I said we talked about that patient previously.

Now, three of these patients were actually very much -- even though they were living in our area, they were attending Cardiff. They were tested in our area but they were seen more in Cardiff. So all of the patients, as far as I remember, once the results were there, the patients were informed within the week. So the patient would be called back in as soon as the result is.

As I said, that was not difficult, given the small number of patients we had to deal with, and there were two of us.

Q. Then the process for testing for hepatitis C, I think

your statement tells us this began in 1990, can you recall over what period that process took place and whether it involved more than one type of test?

A. Well, unfortunately, I can't give you the details because we started in 1990 because I found the earliest positive result in 1990. Unfortunately, the virologist who was doing all these tests has since passed away. So there was first generation, second generation, and God knows how many generation of tests, but I remember that as soon as the test became available, the haemophilia nurse contacted -- I think she started with the severe haemophiliacs and said, look, you know that you've got this what we call non-A, non-B; yes. We've got a test for it, and she actually arranged the test. She would give the patient the form for the test and I think I've sent you one request form which you could see her handwriting. That's not my handwriting.

The result would come to her and I've seen some of the results where they came -- I've written her name -- to [her name], and she would see the patient. Unfortunately, at that time, as I said, we did not have a proper haemophilia centre. So she would call the patient in and tell them the results and I think what she said, look, if you want to see Dr Al-Ismail

or Dr Beddall, you just let me know. I think I've only seen one or two after she gave them the result on their request. Most of them were seen on the ordinary out-patient clinic.

Q. Did you receive the results of the tests yourself and see them before they were communicated to the patient or was it something that was left to the nurse?

A. No, the result of the test would have come to the secretary and the secretary would have passed it to the nurse but I've seen, at least in one of the tests, the result actually was put on my desk, and I've written "to [her name]", to be given the form, so she could communicate the result to the patients.

The number was, you know, in their 30s or 40s. So the number was much larger than the HIV and I think most of the ones who came positive had a notion that they probably would become positive, because they were told that they've got abnormal liver function tests.

Q. If we just look at your witness statement, paragraph 130, doctor, it's WITN3761005 and it's page 41, please. WITN3761005. I think I might have given you an extra zero there.

My screen's not working. Is your screen working, sir?

SIR BRIAN LANGSTAFF: The last thing I've got is:

"My screen's not working. Is your screen working, sir?"

So I think it is.

MS RICHARDS: In terms of the actual ability to see the documents.

SIR BRIAN LANGSTAFF: Yes, I've got the document, page 41.

A. Do you want me to tell you the references I've got --

MS RICHARDS: Don't worry. I think everyone except me has probably got it.

A. Okay, sorry.

Q. It's paragraph 130 of your statement, in any event, doctor, if you have that?

A. Yes.

Q. This is as at 2006, you say 22 had blood borne virus infections which was made up of four patients co-infected with HIV and HCV and 18 that had HCV only?

A. Yes.

Q. So that's 22 patients with hepatitis C, of whom four were co-infected. That's by 2006, I think the number you gave us a moment ago was you thought the magnitude of the patients infected was in the 30s or 40s. Are you able to be more specific?

A. Yes, that may be in 2006, but then if you look at the number of patients in 2019, there were 25. So, yes, I apologise.

Q. That's all right.
A. May be a bit of an exaggeration.
Q. Did you have any system in place or take any steps to check whether patients were being informed of their diagnosis promptly by the nurse?
A. Because the nurse really was concentrating on the one issue at a time, I believe that she informed them promptly, knowing our patients they were in a, sort of -- really quite well informed and had good relationship with the -- in terms of the Morriston Hospital. I would be very surprised if they did not know the result within a week or two, very, very surprised.
Q. Would you expect --
SIR BRIAN LANGSTAFF: Just a moment. The question actually was whether you have put any system in place or whether you checked to see that had happened? I understand that you are saying you assumed it had.
A. Yes, I assumed, yes.
MS RICHARDS: Sorry --
A. I was thinking of a proper system in place to say, look, you had the -- I told the nurse what needs to be done, and the issues need to be discussed and if the patient was to be seen by a consultant, to be seen, but apart from that I did not check on the, if you

like, the execution of that request.
Q. Your statement suggests that the nurse might have informed some patients by telephone?
A. Yes.
Q. Do you know that to be the case, that some patients were told by telephone?
A. I don't know but I wouldn't be surprised because, as I said, patients would probably, if they don't come to the centre. I could see it from the correspondence that she had difficulty in getting the patient to come and see her on a regular basis. So if the patient had called,saying what my results was, I wouldn't be surprised that she told them the result and gave them the offer to be seen by the consultant, if they want.
Q. Would you expect the nurse's communication of that diagnosis whether by phone or in person to be recorded in the notes?
A. That I do not know, and knowing the situation of the notes and their availability when we did not have a proper haemophilia centre, the notes would have been in the general records. It would not be in the haematology department. It's only when we moved to Singleton that we kept the haemophiliac notes in the Haematology Department.

So whether the nurse did manage that, I'll be

very pleasantly surprised if she did.
Q. What arrangements were made at the centre for the counselling of patients, first of all, who were infected with HIV after the test result? Was there any ongoing psychological or equivalent support available for them?
A. No, we did not have any but, I tell you what, we offered every single patient to go and see Professor Bloom at his department in Cardiff because they really had more facilities, and we had one psychiatrist who actually was helping us with the patients with haematological malignancy and we -- if there was any issue with any other patient to be counselled, we would have referred to him. But I can't remember any particular patient who had maybe requested they need that.

So the quick answer to your question: unfortunately, we did not have anything until 2004 in terms of a proper psychological counselling attached to the haemophilia centre. Prior to that it would be Cardiff or whatever help we could muster in Swansea.
Q. You said in a moment ago "2004", do you mean 2014 which is what your statement suggests?
A. 2014, I beg your pardon. You are absolutely right.
Q. In terms of HIV care, to what extent was HIV care

something that you undertook or did you make arrangements for referrals for specialist assistance?
A. Okay. When the HIV start to -- patients come through, first of all it started with the homosexual and drug addicts and my colleague, who -- the late, great Cobbold was -- came to see me and said, look, some of these patients will need to be admitted, because they are immunocompromised it would be best if we could have a look at them together.

Then there was a new consultant respiratory position appointed and we actually recruited him into this group of clinicians to discuss any patient. So that started with the patient with acquired immune deficiency outside haemophilia. When the haemophilia patient started to occur, then that arrangement continued until the need or the availability of treatment for the patient and the appointment of a specialist, a genito-urinary physician, who took specialisation in HIV. I think he was appointed in 1995 or 6 -- I can't remember.

But he was appointed to look after the non-haemophiliac HIV population. When he settled down and I've asked him whether you would consider seeing the haemophiliacs, he said the only place you could see them is in the genito-urinary clinic and he would

not have -- you know, we did not have the ability to come and do a joint clinic with us.

So I put it to the patients. Some of the patients agreed to it, some of the patients actually reminded me saying, look, do you mind if we go to the genito-urinary physician, and -- but some of the patients refused point blank to go to the genito-urinary physician department. I remember one particular patient, fortunately that was the only patient who did not require any treatment for HIV, but he said he would not go to the genito-urinary department to be seen, and I suspect if he would need to have anything done he would have to be seen with the genitory physician in my department.

The good thing we had is that we were able to monitor CD4:CD8, long before the HIV came in. We had a flow cytometer and we were using that for haematological malignancies. So when the HIV hit us, both in terms of the homosexuals, the drug addicts, as well as the haemophiliacs, we were, if you like, the centre who would do the testing for these patients, both for us and for the West Wales, whatever, if anybody who wants to have a test on their patients.

For our patients, we kept the records in the notes, as well as giving it to the genito-urinary

physician. For the patients who is entirely under the GU physician we sent the results to them. So we know what is happening to our patients, even when they were referred to the genito-urinary physician in terms of the CD4 count. Needless to say, we also saw them regularly in the out-patient clinic and asked them if they have any symptoms and whatever, and offered them the prophylactic treatment and whatever.

Q. In terms of the patients who were diagnosed with hepatitis C in the 1990s, were they all referred to, I think, your colleague, Dr Kingham, for assessment and management or did that vary depending upon the particular circumstances of the patient?

A. Did I hear you right, you said hepatitis B?

Q. Hepatitis C. So after they were diagnosed with hepatitis C in the 1990s, did you refer all the patients who were hepatitis C positive to Dr Kingham?

A. Yes. Before we referred, we told the patient would he like to be referred to the liver specialist. Some of the patients said, do they have any treatment for me, and we'll say, well, as far as we know we don't have any treatment, but they could monitor you. Some of them accepted, some of them refused, and even when the treatment became available and I remember, you know, some of them were very well informed professionals,

and I said, look, treatment is now available would you like me to refer you to him, and they said, look, we read about the treatment and, because we feel okay, we don't want to be referred.

But when the, you know, the proper treatment came through later on, they all accepted referral. But before referral was made to the hepatologist, each patient was asked whether they accept the referral and they said, yes, they were referred.

Q. If we have up on screen, please -- and I'm now looking at arrangements for specialist liver care in more recent years. You've told us in your statement that after 2006 patients could be referred to a consultant physician with a special interest in liver disease.

Then could we have ABMU0000021, please.

You will see this refers to an issue about -- this is from 2011 -- about access to a fibroscan, and the hope being expressed by the specialist physician to you is that they were hoping to have one soon.

Can you recall how long it took before fibroscan provision was available for patients in your area?

A. Well, I know we've got it after the Royal Gwent but I can't tell you the exact year. But we certainly -- I think, as I said, we were lucky in Swansea in terms of hepatologist service. We had two clinicians, one

was Dr Kingham and then the other was Dr Chin Lye. Dr Chin Lye actually was -- his particular interest, and was very active, in looking after these patients. But I can't tell you exactly -- you may find the answer in the original statement in 2018, because he gave me a briefing about liver services when I asked him to give me a briefing about liver services to present to the Chief Executive to include it in her response to the Inquiry. I can't tell you exactly but I know it was not long after Royal Gwent that we got ours.

Q. Do you recall from your own knowledge whether there was any difficulty in obtaining funding for treatments for your patients for either HIV or hepatitis C?

A. No.

Q. So you didn't experience difficulties in obtaining funding?

A. No, I didn't -- I mean, I -- actually, if you go back to the top of this letter, if you go back, and you could see that the -- I sent the letter to Dr Chin Lye, copied it to the radiology, copied it to the finance department, copied it to the manager Swansea locality, to tell you that we really needed to have as much pressure as possible to say that, look, we really need, desperately need a sort of a proper

monitoring of these patients.

So I suspect, you know, sort of this may have been -- this letter was prompted by the Task and Finish Group to look at the haemophilia services and whatever -- and what things we provide to them. But I do not remember either the GU physician or the hepatologist saying to me they are experiencing difficulty in getting proper funding for drugs.

I know that Dr Chin Lye actually got the protease inhibitors initially for some of our patients because he recruited them into national and internationally, and that's how he got the protease inhibitors. But as soon as the protease inhibitors became available, I know that it was made available to all the patients. And I'll tell you that I know that because I was chairing the medicine group, which is part of the WSMG, that is to monitor the entry of drugs in Wales, and Wales was one of the first who actually allowed all the protease inhibitors to be available to hepatitis C.

Q. Dr Al-Ismail, I'm not going to ask you about the detail of the vCJD notification process because we have quite a lot of documentation about that, but can you recall whether and if so to what extent patients' statuses of being at risk for public health purposes,

did that cause difficulties for them in terms of accessing surgery and the like or cause deferments of surgical procedures?

A. Well, not in terms of accessing surgery, definitely none whatsoever, but in terms of deferring, unfortunately some of the patients forgot to tell the person they were referred to, and when they were referred without our knowledge, and by our knowledge, the haematology department knowledge, the -- whoever had accepted the referral on the surgical side or the endoscopy side would have written to me saying: what am I to do in terms of treatment of this patient?

We picked some of these patients through this way, saying: look, just hold on a sec, this is a patient who needs special arrangements for the endoscope because it has to be quarantined, or for the equipment, if they are not disposable, to have to be quarantined, did you know about that?

And, of course, you know, you tell the patient, the patient forgets, GP sometimes forgets, colleagues who have been circulated with a different notification forget. So -- but in terms of accessing surgery or accessing endoscopy or accessing any service, no patient was refused such intervention based on their risk factor, but some of them may have been given an

appointment but that appointment had to be altered simply because it came to the attention of the treating surgeon or physician that special arrangements need to be made.

Q. Dr Al-Ismail, I have a handful of questions suggested by others that I want to ask you about next, so we may dot round from topic to topic now.

Could we have, please, the doctor's witness statement back on screen. WITN3761005. And could we go to page 20, please.

If we look at the bottom of the page, paragraph 66, you have referred there to cryoprecipitate being used for patients with hypofibrinogenaemia, and you explain that's a rare bleeding disorder. How much cryoprecipitate did patient with that condition tend to require?

A. They usually require about ten packs. And it is something which is -- people still were using even just before I retired. Simply because fibrinogen was not licensed. I know that some of my colleagues in Cardiff were using fibrinogen but we continued to use cryoprecipitate in patients who have hypofibrinogenaemia. We continued to use cryoprecipitate in patients who needed massive blood transfusion. We had a cardiac centre and so there are

patients who would have, you know, bypass surgery, patients who would have valve surgery, and they usually would require cryoprecipitate simply because they would have massive blood transfusion.

So the usual thing is to give 10 units of cryoprecipitate, check their fibrinogen level, make sure it is above 2 before you stop giving them cryoprecipitate.

Q. Were any such patients in that category infected with HIV or hepatitis C as a result of their treatment?

A. Not to my knowledge. Mind you, I think since the -- you know, that all donors were checked for HIV and then, later, for HCV, then all the donations were fine. But you can look at cryoprecipitate, in that context, in a very similar way to looking at a unit of blood, because many patients were transfused with blood at times we did not know about hepatitis C, and testing for hepatitis C really was not done afterward. And one of the things which I personally believe, in that every patient who had a blood transfusion or blood product should have a test for hepatitis C. It's such a simple test and the treatment is so effective.

Q. You said during the course of your earlier answers this morning that when you were trying to find out

what the various stages were for ordering products, you couldn't access all of the blood transfusion records before 1984, and you said that that was possibly something to come back to. Could you just expand upon that, please?

A. I think you have sent me a document last week, and that is why I thought you may be coming back to it. So let me tell you a bit more about this.

So prior to 19 -- up to 1980, all the blood transfusion documents, that is blood and blood products on part of haemophiliacs, were actually paper documents, and they were since, being many years, been lost.

Then between 1980 and 1984 we acquired the computer system called TelePath, and -- oh, maybe before that we acquired a computer system.

Anyway, so at 1985 that was changed. It may be changed to TelePath, and we were told that the previous computer system we -- would be microfiched and stored. And -- but that actually -- it was microfiched but it was unrecoverable, I was told by the head of blood transfusion, when the first request from the Infected Blood Inquiry came to the Chief Executive.

In 1985 to 1981 was TelePath, and this is the

one which was microfiched. And then after 1991 until 2003 we changed to another system, called ACT, and when that laboratory system moved to another system, called MasterLab, in 2003, all the documents were transferring to MasterLab.

So anything really which was in TelePath -- if you like, you would not be able to get any documentation after 1991 from our computer system, unfortunately.

Q. After 1991 or 1981?

A. 1991. So after 1991 -- before 1991 you could not retrieve anything.

Q. Are those records of blood transfusions?

A. Yes.

Q. They are not records relating to haemophilia patients or do they --

A. No, no, the haemophilia records were separate, really, because, you know, sort of all the time we gave a unit of cryoprecipitate or a unit of -- or a bottle of concentrate, that was documented in the patient notes and then transferred to UKHCDO. So that's different.

Q. Next question, doctor, you will recall this morning we talked about the annual returns and the fact that DDAVP doesn't feature on the returns until 1985.

You thought that an explanation for that might

be that DDAVP was ordered by the pharmacy and that its use may not have been communicated to the person completing the returns. Who was it who completed the returns? Was it the centre director?

A. No, I wish. Well, the centre director, as I said to you, would not have the time to complete the returns. These returns have to be done on a daily/weekly basis. So it was the MLSOs -- and I'm ever so grateful to them because it's not really part of their job -- until the haemophilia nurse was appointed, and then the haemophilia nurse was filling the returns. And we -- as the director, whether it's Dr Khurshid or myself, looked over the returns and made sure that there is no major inaccuracies.

But the DDAVP would be ordered on a drug chart, and it still is, which would go to the pharmacy and the pharmacy would issue the DDAVP. So unless we highlight that to the person who is doing the return, the person who is doing the return would not know about it.

When the haemophilia nurse came in, then she would know exactly what each haemophiliac patient would have received for any particular treatment. So any DDAVP would be entered in the patient notes and would be on the chart, so she would know about that.

But the MLSOs, if we do not communicate that information to them, they do not see the patient notes on a regular basis or they don't even see the patient notes, so the onus really was on us to communicate that to them.

Q. We can see that the 1985 return does record DDAVP. Why, if it was being used earlier than that, was it not recorded on the 1982, '3, '4 runs checked by you and Dr Khurshid?

A. Well, I mean, you are asking me something which I can't give you the answer to. 1985, I took over checking the returns, and I'm sure -- you have to remember, when Dr Khurshid was working, and until I came to the scene, he was working single-handed. He was doing all the things that two haematologists did, then three haematologists did, then four, five, six -- six haematologists did in recent years. So, you know, there is a limit to what a person could do.

But I agree if you want for the record, then you would need to record everything about the patient. The only tragic thing is that if we did not have the destruction of the notes of the haemophiliacs, this Inquiry would have been much better informed about exactly what happened.

Q. Just picking up on that, doctor, what notes relating

to haemophiliacs were, to your knowledge, destroyed within Swansea?

A. Well, Swansea, and if you look into the Chief Executive response, has a destruction policy for notes. And I don't think they differ in any other health board in relation to that.

The haemophiliac notes, when we moved to Singleton, were kept in the haemophilia centre. But when a patient dies, very often the notes would be taken by the medical records to prepare the death certificates. And unless you insist on the patient -- on the notes being returned because you wanted to complete one thing or another, then that would be put in with the other notes, and I think after eight years or whatever they would have been destroyed.

As I said, I think one of the good things that happened in Cardiff is that somehow they stopped the destruction of these notes by pleading with the managers and whatever. And I wish I, you know, sort of -- or Dr Khurshid or any one of us had done the same. And to be honest with you, until the Inquiry came into one of the patients who was a mild haemophiliac and then -- I mentioned him earlier, and I've put him in my statement -- until that patient I was told that they could not find the notes of,

I said, "Look, it's only a few years ago, two years ago that I got the notes, how come the notes are not there?"

"Oh, because they were destroyed."

I did not know about that policy about haemophiliacs until that time. But it is one of the things which, you know, sort of -- it would have helped immensely, either the Inquiry would have taken -- been conducted many years back or we did not have any destruction of the notes. Because then you would have the facts as -- not just trying to recall from one's memory 30 or 40 years ago.

Q. I asked you earlier about the treatment policy in relation to mild haemophiliacs and you discussed the possibility of treating a mild haemophiliac with concentrate if surgery was required. Between 1980 and 1985 or 1986, when heat-treated products became available, what would the treatment policy have been for a mild haemophiliac who required surgery if there was no NHS concentrate available and so the choice was between cryoprecipitate or commercial concentrate?

A. Heat-treated or not heat-treated?

Q. Not heat-treated.

A. Cryoprecipitate would have been preferred. But if it is surgery, it would have -- if it's surgery, that

meant that you really need to achieve haemostasis with 50 -- with levels between 50 and 100 per cent, if you like, in simple terms, all the time for ten days, then the only way probably would have been concentrates.

Q. I asked you questions about discussions that you had with Professor Bloom about the risks of AIDS. Did you ever ask Professor Bloom what advice he, Professor Bloom, was giving to his patients about the emerging picture on AIDS?

A. I think Professor Bloom has, as I said in the morning, had a few meetings, and we encouraged our haemophiliacs to go to the same meetings, really, and he called them all to -- I think he -- to a lecture theatre and, I think, explained, you know, the issues as he knew them at the time.

The patients who went from Swansea were, you know, sort of quite comfortable with the meeting. I did not have any negative things to say from any patient, you know, sort of reflecting back on the meeting to me. So that is what happened.

And as I said, The Haemophilia Society had regular meetings, The Haemophilia Society sent regular, you know, sort of leaflets to patients. We had a stand in the haemophilia centre in Singleton Hospital whereby we kept these leaflets, including The

Haemophilia Society leaflets, and I distinctly remember that every time the haemophiliacs would come, the nurse would say, "Look, have you got this leaflet, have you got that leaflet", and -- you know, so she usually prepare a pack for them and give them -- do that with, you know, whatever else she had in terms of, you know, sort of freebies and whatever to them and to the children. So that is the way it was communicated to the patients.

Needless to say, if patients either tested positive or before they test positive had requested any information, we would have sat and explained to them whatever we could. I said that, and I'm repeating myself again here, is that I kept saying to my patients that I cannot speculate but I'll tell them the fact as I know them.

Q. Just to go back to my question, doctor, did you ask Professor Bloom what advice he was giving to his patients about AIDS?

A. I did not.

Q. Do you accept that there maybe had been haemophiliacs or patients with bleeding disorders who were not members of The Haemophilia Society or not regular attenders at a haemophilia centre or regularly engaged with The Haemophilia Society, particularly if they

were infrequent bleeders and had mild or moderate haemophilia?

A. Would you like to repeat the question again, please?

Q. Of course. The question, Dr Al-Ismail, arises out of your evidence that you thought patients were very well informed and they had access to information from The Haemophilia Society or from the nurse at the centre, and so on. Do you accept that there may have been patients particularly those with mild or moderate bleeding disorders, who may not have engaged with The Haemophilia Society or the centre on a regular basis and may not have had access to information?

A. I suppose there's always that possibility and they haven't read the newspapers and they haven't seen TV, there's always a possibility.

Q. In relation to the authorisation of purchases for commercial products, you said earlier you didn't sign invoices or the equivalent. Do you know who did, not necessarily by name, but in terms of the role or job description of those who signed the invoices or authorised the actual purchases?

A. It would have been a finance director of -- it would have gone to the finance director's office and, you know, whatever arrangement they had there.

Q. To your knowledge in the 1980s, did the Welsh Chief

Medical Officer play any part in arrangements for the supply of blood and blood products in Wales or in providing information to consultants, such as yourself?

A. I don't know anything about that, really. I don't know whether they had anything. I know that they were never named in any litigation but I don't know whether they were engaged in any way, in relation to blood or blood products.

Q. Then your returns for 1985 and 1986 show that, in relation to patients with haemophilia B -- and I think the returns prior to that show no patients with haemophilia B -- you were using predominantly or exclusively commercial Factor IX concentrates. If we could have up on screen please, Soumik BAYP0000008_084.

Go to the last page of this, please. This is another internal Cutter document, doctor. We can see at the bottom paragraph -- sorry, the last paragraph, please -- it says:

"Most English centres are receiving NHS Factor IX. Swansea is an exception."

Can you recall why you were using predominantly commercial Factor IX products in 1985 and 1986?

A. Yes, I do. If we go to -- do you have the returns of

1985?

Q. Yes, we do. It's WITN3761008. If you go to page 28, please, Soumik. So that's haemophilia A. If you go on two pages, it should be the return for 1985 for haemophilia B.

A. As you rightly said, up to 1984, we didn't have a single patient with haemophilia B. In 1985 one patient, a 39-year old came in, he actually moved from London to us. He was in St Thomas'. And I had a letter -- the reason why I recall that so vividly is because I only looked at it last week.

I had a letter from St Thomas' to say that so-and-so is a patient with severe haemophilia B and he's moving to your area. They did not tell me what the patient was on, so the first question -- he was actually seen by my colleague Dr Beddall on 2 August 1985, and Dr Beddall recorded that the patient is on heat treatment product and that is -- I could figure out from the notes. So that is why he went on heat-treated product.

I can't -- you know, could not find out whether he was started on Alpha and then Cutter or vice versa, or whether we started on the same one as he was in St Thomas' because St Thomas' letter did not tell us exactly what products he was on, and my colleague has

written to Dr Savidge at the time saying can you please give me full details of what the patient was on, and I could not find a reply in the notes.

So the reason why we've used the commercial one is because the patient was already on heat-treated and he was, again, a well-informed patient and he asked for heat-treated. At that time we did not have heat-treated Factor IX.

Q. You didn't have heat-treated NHS Factor IX?

A. Yes. If you go to the year after, that is 1986.

Q. That should be if you go to page 35, possibly, Soumik. Yes.

A. This time there's another patient. This was a 19-year old who joined the Swansea University, and he was a severe haemophiliac and he was already on NHS Factor IX, so he continued on NHS Factor IX and the patient on the heat treatment product was continued on the Cutter product. So that is why, I suppose when you have one patient in 1985, you'd be the odd-one-out that is why Swansea was the odd one out.

SIR BRIAN LANGSTAFF: Just pause for a moment. At this time, 1986, there would have been heated Factor IX, would there not, from the NHS?

A. Yes, I think so.

SIR BRIAN LANGSTAFF: Thank you.

MS RICHARDS: You referred a few moments ago to a meeting or meetings which you understood Professor Bloom to have arranged in a lecture theatre, or equivalent, in Cardiff. Do you know approximately when that took place?

A. No, unfortunately, I can't tell you, but it was soon after the -- I think -- I don't know whether it was before his patient developed acquired immune deficiency or -- I can't tell you.

MS RICHARDS: Sir, those are my questions for Dr Al-Ismail. Do you have any questions for him?

SIR BRIAN LANGSTAFF: Yes, I do just a few, if I may, doctor. Can we go back to your witness statement at page 18. You were asked about this this morning.

A. Yes.

MS RICHARDS: WITN7631005, page 18.

SIR BRIAN LANGSTAFF: Thank you. you were asked about paragraph 56. Now, so far as choosing or selecting a particular product was concerned, you didn't have to ask anyone's permission to select which product to use, did you?

A. Well, I would ask have asked Professor Bloom and Dr Khurshid would have asked Professor Bloom.

SIR BRIAN LANGSTAFF: For permission?

A. Sorry?

SIR BRIAN LANGSTAFF: For permission to buy the product or just for advice as to which to buy?

A. For advice as to which to buy. The problem I had actually in figuring out how did we buy these products, did we buy them directly, did we -- because there was a paper by Rizza et al that talked about -- I think it's one of the documents which you've sent me -- talked about the management of haemophilia in the UK between 1980 or 1991, or whatever. I've got the reference to it if you want and in one paragraph of that paper, it said the commercial product were supplied free to the haemophilia centres in England and Wales until 1992.

If you ask me what did that occur or did not that -- and I actually put it in my statement, I said I believe that the commercial product were supplied free based on that paper. The bottom line is I did not know what were the mechanisms of purchasing a product, whether in a, sort of, my health authority was solely responsible for it, or was there a central funding which the health authority had, but in terms of which product to select, Professor Bloom would have been asked what his opinion and we would usually follow it.

Does that answer your question?

SIR BRIAN LANGSTAFF: Well, it does. You've said, which is consistent with the evidence you gave about when you went with Cutter, you said you'd asked Professor Bloom for his opinion and he'd given you it. But it's in relation to 56(ii). You didn't know the mechanism for purchase. When selecting a product, I understand that you relied heavily upon what Professor Bloom was telling you, but in your answers you gave a further reason, I think, which was that the product had been licensed and you took it on trust, as I understand.

A. Yes.

SIR BRIAN LANGSTAFF: So when the -- this paragraph begins:

"... the basis of decisions made about the selection of a particular product or particular concentrate for an individual patient."

Safety and efficacy came into that. Did it come into that and, if so, how, if what you were doing was placing your trust in the advice of Professor Bloom and the decisions of the regulator to allow product to be sold in the UK?

A. Would you suggest any other way of putting my decision, because the -- since the Thalidomide disaster happened, no product should have been

authorised for human consumption in the UK unless that product has been passed by the -- what is the equivalent of the MHRA previously, that the product should have shown safety and efficacy. In other words, we did not use any product which is not licensed.

Professor Bloom's advice would have been on the basis that he would have an experience in what product would probably be more -- be better than others in whatever measures he used. So the safety and efficacy of a selected product, I personally would not have any other way of assessing that.

SIR BRIAN LANGSTAFF: I see. So this was really relying upon the regulator doing its job properly and, for that matter, those who had more experience, perhaps, in treating those with haemophilia giving you their best advice?

A. Absolutely.

SIR BRIAN LANGSTAFF: Thank you. Do you have anything generally to say about what experience has shown you, from your experience, about the nature of the quality of the product that the regulator permitted to be used in the UK?

A. Well, do I need to say much except that, you know, if the regulator had known or had any information about

the source of donation which had been used for any product, these products should not -- in my opinion, should not have been allowed to be marketed in the UK.

Unfortunately, and I say that with, you know, heavy heart, really, that even in the UK, you know, the Blood Transfusion Service relied on sourcing blood from prisoners at some time I was told. I can't tell you the figure but I'm sure you would have access to that information.

I think if the regulator had any information about the skid row type of donations that were used to prepare the product -- foolishly, probably they thought hepatitis B, once it's excluded everything is fine. And that is clearly not a way forward for anybody who would think at any time, even now, that we know everything about what blood and blood product could transmit.

So, yeah, I think the regulators at the time has really failed in making sure that whatever is marketed in terms of blood and blood product, whether that is from abroad or from the UK for that matter, should really have had probably proved more safety than, you know, sort of just to be taken that hepatitis B was excluded.

SIR BRIAN LANGSTAFF: Can I turn to something else.

You said, in one sentence which caught my ear in particular, in haematological malignancy you truly can't take a decision for a patient. That was my note of what you said. What struck me about that was the word "truly"; you truly can't take a decision for a patient.

Does that reflect your general understanding that other clinicians in the country sometimes did take decisions for patients? There were certain circumstances in which you in particular found you simply couldn't?

A. I can't speak in general like this but I know that --

SIR BRIAN LANGSTAFF: Well, I'm asking you about what you said, you see, and the word "truly" did strike me.

A. I was trained in, in terms of haematological malignancies, in Cardiff, and that was most of the training. I remember what my consultant, Mr Jack Whittaker, used to do with leukaemia, and I sat with him and -- when he discussed a new diagnosis with a patient and their family, and I was taken back for the first time I noticed that a consultant cannot really tell the patient what to do. I did not -- you know, it's not something which you experience before when you become a junior. You think -- in medicine, you are always seeing your

seniors and making decision and convincing the patient. In haematological malignancy, it did not work like that because, as I said, even though you may have a good treatment and even though that treatment may actually be curative, you may lose the patient just through the side effect of the treatment. So you explain to the patient what are the risks and possible benefits and then you put it to the patient and ask them for a decision.

Very often and most of the time the patients will take the decision that they would go for a particular treatment. But I had a number of occasions when I was a consultant and I sat with a patient and explained the diagnosis and the treatment, and the fact that once I start the treatment they have to spend about a month in hospital before the second course of treatment, and then they ask me what are the chances of them recovering completely and I explained the percentage, they turned to me and said, "No, thank you very much. I'd rather go home and come back to you and have a blood transfusion whenever I need it, and how long am I likely to live?" And I would say, well, you know about half of the patients will die within three to six months. And he said, "I'll take that". I had

that occasion.

And so -- and I think that in a way is the current thinking, not just in cancers and haematology and whatever, in modern medicine is that you really explain -- you try to empower the patient, to give them as much knowledge as you can convey to them in as simplified way as possible without going into details of path of physiology and whatever, and try to get the patient to make the decision for you.

SIR BRIAN LANGSTAFF: So the way you see it, is it, is that treatment is something that is done for a patient rather than done to them?

A. Yes. My role is to explain to the patient to the best way I can as what are the conditions they have, what is the ailment, what can we offer them, what does that mean in terms of their quality of life, what does that mean in likely change to their longevity and their survival, and may even when they ask for a graph, show them the graphs, and then ask them what they want to do. And try to encourage them not to make an instantaneous decision, try to encourage them to go away, read about that. I always told patients when the internet became available: please do go on the internet if you wish to go on the internet, read as much as you like, come and talk to me because I would

only tell you what I know as facts.

I found that really so easy with the patients, because I don't really need to write in full details every single word I've told the patients. I would almost certainly know what I have told patient A and patient B, because it will be exactly the same.

SIR BRIAN LANGSTAFF: The next question I'd like to ask you, again comes from something that you were describing, which is when you were talking to patients about HIV, and you said the conversation might go something like, and you described how the patient might say, "Well, will I die of it?" and you'd say, well, you don't know but you will be checking.

A. What I would have said -- I said some patients would die. How long -- whether you would be one of these -- this is the very early days, when we did not know how long a patient is going to be. You see, if I could take you back a bit, when people started talking that this acquired immune deficiency is all related to antigenic stimulation. Now if that was true, that meant some patients may have this antigenic stimulation for years but they did not show any problem with HIV, while others are showing it now. Even when the virus was discovered and we found that it is a virus which is causing it, the number of

patients going down and unfortunately succumbing to the infection, initially, were very small, compared with the positivity in terms of antibody, and we thought, or we hoped, that it is going to be something which is not that disastrous.

Unfortunately, we all were proven wrong and I think that is, in a way ... yes, that was the tragedy, really.

SIR BRIAN LANGSTAFF: Do you want to say any more about that?

A. Well, not in the sense that, you know, sort of -- you know, the initial thinking that the HIV maybe is going to be different in the haemophiliac -- on the other patients' group, because the haemophiliac did not have any other what we thought contributing issues, all proved to be wrong.

SIR BRIAN LANGSTAFF: Do you think that you, collectively, erred on the side of optimism?

A. Yes, I think -- and I think the reason why we erred on the side of optimism is because, if you like, by the time we -- the test became available to us -- and as I said, all the patients with the first lot of testing proved to be positive, and we -- really, that was the -- if you like, the only thing you could do, in the sense that if you did not err on the side of

optimism, it would have been very difficult to continue with one's career really.

There isn't a treatment. There isn't anyone who will tell you in which path these patients are going to go. At least in haematological malignancy you have so many parameters that you could plot and you could say to the patient: this is the patient in the very high risk group, this is the patient in the lower risk group. You didn't have any of that. The only thing you had was to watch and wait. And until such a time as then the -- you start to learn what to try to avoid or protect the patient against in terms of infections, and you use that. But these were all, if you like, preventative of secondary infection. It was only when the real treatment came in that we could see the light at the end of the tunnel.

Prior to that it was terrible.

SIR BRIAN LANGSTAFF: Hepatitis C or non-A, non-B, I think you described a very similar conversation that you might have in respect of that, that you didn't know what the consequence of that infection would be, but we'll keep checking.

How would you have checked? How did you check?

A. Well, by, as I said patients, would have maybe once a year ultrasounds of the liver. Looking for the

stigmata of liver disease, because when you start to develop cirrhosis there are certain things which you could see on the skin. You could see on the palm of the hand, you could see in the development of ascites you always relied on your hepatology colleague to have a look at your patients every now and then and tell you, well, nothing has changed really, the patient is told the same. The hepatologists are very familiar dealing with different liver disease the auto immune disease, the alcoholic liver disease, the different type of liver diseases. So they really have a better understanding of what to look for in a patient.

I remember, and I think the Inquiry have asked me about one particular patient I referred to Dr Kingham, and his registrar wrote to me back saying "We're going to adopt a policy of watch and wait", because they knew what they were doing. They were testing for the virus in the blood but they knew what are the issues to look for. Liver biopsy, certainly in, you know, in my practice or in Cardiff practice was not something to be undertaken lightly.

Later on when Dr Chin Lye came to hepatology he actually could do liver biopsy through an endoscope, so if there would be any bleeding it will be much manageable, but he did not do it any of the

haemophiliacs. Then the issues, you know, about FibroScan became available and, as I said, with the hepatitis C, I think it is a sad story, but the happy ending is that, for the vast majority of the patients, the effective treatments came into effect, and I think, or we're hoping that all these patients would have a normal life expectancy.

SIR BRIAN LANGSTAFF: Thank you. The last thing which I want to ask you about is in respect of the number of patients of yours who converted to HIV seroconverted, and I think you said there were eight.

A. Yes, six adults and two children, yes.

SIR BRIAN LANGSTAFF: Now, roughly what proportion of those patients that were loosely under the care of the Swansea centre, roughly what proportion was that?

A. What proportion of all the patients?

SIR BRIAN LANGSTAFF: Yes.

A. So it's eight out of -- I think at that time we probably had 60 patients, so 8 out of 60 or 68 patients. So it's about -- you know, more than -- it's about 12 per cent.

SIR BRIAN LANGSTAFF: Yes. We get -- 8 out of 60 might be 15 per cent, perhaps, but it's something of that order.

The reason I ask -- oh, let me ask, how many

severe haemophiliacs were there in that 60 or so? Roughly.

A. I think all the severe haemophiliacs became HIV positive.

SIR BRIAN LANGSTAFF: Thank you.

Do you have a reason that you can tell us, from your experience, why you think it was that all the severe haemophiliacs should suffer from HIV infection and largely the mild and moderate haemophiliacs did not?

A. Well, it's all to do with their treatment. It's all to do -- I think "should" is not the right word, with all respect. They were unfortunate to suffer with the HIV simply because the treatment they needed conveyed that infection on them.

Now the mild who -- the occasional mild who may have had a concentrate, you know, on the laws of probability it's probably that concentrate did not carry the virus, but for the severe haemophiliacs, the number of infusions they would have, they would be very lucky to escape the HIV virus, considering the fact that, you know, sort of the issue probably started in the late 70s and continued until 19 -- you know sort of when the testing of donors for HIV came into practice and the heat treatment came into

practice.

So the number of infusions they had, as I said, would be very, very, very lucky severe haemophiliacs to have escaped it. But fortunately, you know, some of them did survive it, and we managed to get them the treatment. And I hope -- well, there's -- even though, you know, the treatment itself is not an easy panacea, they did have so many side effects with a different treatment, but at least in terms of life expectancy then we would be able to say that hopefully they would live an almost normal or normal life expectancy.

But the unfortunate ones are the ones who actually succumbed to the infection before an effective treatment became available to us.

SIR BRIAN LANGSTAFF: Thank you very much. That's all that I have to ask.

Ms Richards.

MS RICHARDS: Dr Al-Ismail, is there anything further that you wanted to say?

A. If I may, I would like to make a brief comment really, a brief statement. Would I be able to do that?

MS RICHARDS: Yes.

SIR BRIAN LANGSTAFF: Yes, indeed.

A. Well, I've written it down so I didn't want to miss

any important points.

What I'm saying is that I firmly believe that the most devastating experience for a doctor is to witness harm inflicted on his or her patient that resulted from treatment the patient had received. Now, this feeling of devastation is felt regardless whether the harm occurred unintentionally and even if the harm could not have been foreseen.

Now, I've seen that, particularly in the haematological malignancies, as I said some of them are curable, but the patients succumb because of the infection which followed when the treatment -- you know, as a result of treatment and their immune suppression. So that had a devastating effect on the whole department.

Now, I believe that feeling of devastation is shared by many of my current and previous colleagues that looked after the patient with haemophilia and other inherited bleeding disorders. I would like to mention specifically in that context, if I may, the late Professor Bloom.

Now, Professor Arthur Bloom, as I said before, was one of the most gentle, kind, compassionate and caring doctors that I knew. He was also an excellent mentor. I think it is true to say that his main aim

in his professional life was to improve the care and outcome for the patients with inherited bleeding disorder.

Arthur was a wise man, truly wise man and, hence, you find that his involvement in so many national and international advisory groups, really, in haemophilia and allied disorders. As I said before, he was never, never an opinionated man, always listened to the views of his patients and, as I said, he used to sit down on the side of the bed of the patient and give the patient as much time as the patient want, but he also listened to his colleagues.

Now, he taught us about the devastating effect of haemophilia on the life and well-being, not only of the patients but also their families as well. He really drilled that into us. Now, I remember this anecdote, there was a very pleasant young man in his late teens with severe haemophilia. He was from the Far East and was referred to Professor Bloom for advice and management in Cardiff. Now, that patient -- I think that was second or third year I was in Cardiff -- now, that patient had the most deformed joints I've ever, ever witnessed.

Now, I remember I told the other registrars who were not doing haemophilia at the time that we had

that and they would go and ask Professor Bloom whether they could go with him and see the patient because none of us have seen such terrible joints.

Now, Professor Bloom told us that such picture was not unusual, not uncommon in the UK, before the advent of concentrate. Now, I taught medical students, you know throughout my career but, you know, sort of from the 2000s onwards, or maybe before the 2000s, it's difficult when the session comes to talk about haemophilia and try to show them a young patient with haemophilia and at the age of 40 with a deformed joint, fortunately, you will not find one.

I do believe that Professor Bloom became aware, maybe in the early '80s that acquired immune deficiency could be transmitted by treatment for haemophiliacs. I believe that -- not just believe it, I think he may have mentioned it to me that he thought initially perhaps not going to be a big issue. His belief was perhaps based on the small number of the haemophiliacs that showed the clinical disease initially, but he also did the survey in 19 -- end of 1983/84. He published in 30 June, and that survey, as I said, included 13,147 patients, from 121 haemophiliac centres in the UK and Europe, and only 11 out of the 13,000-odd patients had AIDS, like it

was, you know, as we knew then.

I think he thought that, unlike the transmission of AIDS -- and I'm talking 19 -- early 1983 -- that unlike the transmission of AIDS in the IV drug addicts and homosexuals, the causative agent maybe could have been attenuated or modified in the process of preparing the concentrate and that there were other mitigating factors in the non-haemophiliacs.

You know, he wasn't alone in these thoughts. If you look at the publication that came in the early 80s, as to the possible cause of AIDS, the publication -- the number of publications testified that the world leaders in haemophilia held similar views. Now he documented so many of that in the report he prepared in 1989 as part of the defence against the litigation raised at the time.

Now Swansea and its staff and the West Glamorgan Health Authority were never named or never had to answer any litigation in relation to the management of haemophilia or other inherited bleeding disorders. But Arthur sent me a copy of the report, and he did that because some of the patients who he looked after were shared with Swansea, and he said, "You know, I think you should read this". And to be honest, I read the report and I understood so many of the

issues that must have made him say what he said at the time. Now I'm sure the Inquiry would give due consideration to his report, but I truly wish that his report would be made public, and the reason for that is so that patients and their families could read the facts as he saw them and he stated them in the report.

Now, I knew he was so concerned about the pain and suffering that haemophiliac could endure if the concentrate were abandoned, particularly when there was no credible alternatives. And I repeat I did not think that cryoprecipitate was a credible alternative. Again, that was not just his views but the vast majority of world leader in the care of haemophilia, as well as the doctor specialised in the haemophilia care in the UK, Europe and North America. I think he addressed The Haemophilia Society Council in October 1983 and he said that in his report -- he said that he became more circumspect than previously with regard to blood products and AIDS.

Now he suggested to the meeting at the time, that is in October 1983, two months after the death of his first patient, he asked if the role of concentrate could become -- he said until the role of concentrate became clearer it would be wise to revise the dosage and the treatment for haemophiliacs and ask if the

haemophiliac could modify their lifestyle to reduce the need for these concentrates.

He reported in his report that he met with very poor reception by the audience, and I've read the same thing in -- when it was mentioned by the National Haemophilia Federation, which is similar to the Haemophilia Society in the US and the World Federation of Haemophilia.

Finally, I explained that the worst nightmare for a caring doctor is to witness the ill effect of the medication on their patients.

Now, I truly witnessed that on Arthur. The last time I saw him was -- was on 18 September 1992. I think it was a UKHCDO meeting. Now, I had not seen him before that meeting for quite a long time, actually, and I was taken aback. You know, whenever we used to meet, he was full of -- he had a big smile on his face and whatever, but he was looking -- he really looked terrible. He was so down and clearly was, you know, sort of -- something which is troubling him immensely. I said to him, "Arthur, what's the matter?" and he said "Oh, it's my gait, I'm having problem with my gait". Then when I pressed him I really did not ... I thought: this can't be true. I asked him about his family, could it be his wife,

could it be his children, and he said no.

Then I really continued to press him because he really looked terrible, and then he looked at me and said -- I'm sorry. He said, "Saad, our patients have come to great harm". Now I firmly believe that the thought tormented him for the rest of his life.

Now that is regardless of the fact that he and my colleague, Dr Les Moffatt, had published a series in 1985 in The Lancet to say that he -- they did a look-back and they found that their HIV conversion started in 1980s. So he knew that he could not have changed much of what happened later on, but that made no difference to him. And I really feel that until he died that feeling of sadness stayed with him. It did not make a difference to his feelings of sadness for the haemophilia patients, what they had to go through and what they are currently going through as well.

Thank you.

SIR BRIAN LANGSTAFF: Well, thank you, Dr Al-Ismail. I'm sorry that we've kept you here for longer than you might have anticipated but you don't have to come back tomorrow.

A. Thank you.

SIR BRIAN LANGSTAFF: I am sorry too for those who have been listening remotely that they may have been on the

screen for much longer than they too had anticipated, because they too are part and parcel of this hearing. But can I thank you in particular for giving us a view of what it was like to be in a much smaller centre, close to a centre of influence and knowledge, in Cardiff, and for giving us your views, from being the trainee doctor to taking up your role in 1984/85 in Swansea at the various places that you operated. The Inquiry is grateful to you for that and for your full answers in your statement. So thank you very much.

A. Of course.

MS RICHARDS: Sir, tomorrow we have Dr Mitchell at ten o'clock.

SIR BRIAN LANGSTAFF: Ten o'clock tomorrow. Dr Mitchell. Thank you.

(5.45 pm)

(Adjourned until 10.00 am the following day)

F:

F:

F:

F:

F:

F: