Thursday, 29 October 2020

(10.00 am)

SIR BRIAN LANGSTAFF: Today we welcome Dr Parapia. May he be sworn, please.

PROFESSOR LIAKAT PARAPIA (sworn)

Questioned by MS SCOTT

MS SCOTT: Professor Parapia, I'm going to start by asking you some questions about your CV. So you undertook your medical training in the early 1970s at the Welsh National School of Medicine; is that right?

A. Yes.

Q. Can you recall what kind of haematology training you had?

A. Well, Cardiff, the Welsh National School of Medicine was very, very strong in haematology, very reputable, some very big names at the time, including Professor Bloom. Even I was taught by Professor Tuddenham but in terms of actually content of the training for the medical school, there was very little time given for haematology.

Q. So you were taught by Professor Tuddenham at university?

A. Well, in the component that he had, yes. So I knew him from then. But, like I said, in terms of the curriculum there was very little haematology.

Q. Then you graduated in 1974 and you became a House Officer at the Cardiff and Carmarthen Hospital and the following year Senior House Officer at Wythenshawe Hospital in Manchester?

A. Yes, that's right, yes.

Q. During your time in those two posts, did you treat any haemophiliacs?

A. None whatsoever.

Q. Then you took up a role as a Senior House Officer in pathology at the Wythenshawe Hospital. What did that involve?

A. Well, first Senior House Officer in medicine, general medicine -- I did a medical rotation and then I did pathology rotation as the Senior House Officer. That means I went through all the components, including haematology for three months, and then I did become registrar in haematology, combining my medical and my pathology training together and, by this time, I had the membership of the Royal College of Physicians.

Q. So you became a registrar in 1977 and that was, again, in the Wythenshawe Hospital in Manchester?

A. That's right, yes.

Q. At that stage, so while you were working there in haematology and doing your pathology rotation, were you caring for any haemophiliacs in the haemophilia

centre?

A. No, none at all. There was no haemophilia centre there. There's a good cardiac unit, et cetera, but no -- haemophilia was being treated at Manchester Royal and at Withington Hospital on the coagulation disorders.

Q. So you had no experience at that stage of dealing with anyone with haemophilia?

A. No, none at all.

Q. Then in August 1978 you became Senior Registrar in haematology between Leeds and Bradford, and you held that post for three years?

A. Yes, that's right, yes.

Q. You rotated between the two, between Leeds and Bradford, did you?

A. Yes, the rotation was divided between Leeds General Infirmary, St James's Hospital, which was a haemophilia centre, Blood Transfusion Service for six months, including paediatrics, and the time at Bradford Royal, which was a haemophilia centre.

Q. When you were at the Blood Transfusion Service what did that involve?

A. That was combined with paediatrics. We learnt about bench work, but I think largely we were really a pair of hands. There was very little what I would call

formal training. But we were, apprentices to the consultants.

Q. So you were -- where physically were you during that period?

A. Blood Transfusion Centre in Leeds.

Q. In Leeds, primarily in the laboratory there?

A. Primarily in the laboratories sort of setting but we were also doing paediatrics at the same time. So we did the paediatric bone marrows, et cetera, giving support to the paediatric oncologist.

Q. While you were in Leeds at St James's Hospital and at Bradford, were you working in the haemophilia centres there?

A. Yes, but the primary focus in both hospitals was to do with chemotherapy and leukaemia and, well, in Bradford solid tumours, lymphomas, and so on. But the haemophilia care, was there, yes and that's where I got my experiences, yes.

Q. So your first experience of working with people with haemophilia was in 1978?

A. In '78 I started at Bradford where the senior registrar, really, was primarily involved in treating haemophiliacs, and then at St James's again, it was really the junior staff that treated the bleeding disorders.

Q. Who was the director of the Leeds centre at that time?
A. Dr Swinburne was -- she wasn't a haematologist, she was an immunologist. She wasn't a clinician but she was in charge of haemophiliacs.
Q. In the Leeds centre?
A. In Leeds, at St James's.
Q. Then in the Bradford centre, it was Professor Turner; is that right?
A. Yes, it was Professor Turner who, by the way, set up the first haemophilia centre in the country, it was in Bradford. So he was quite instrumental. In his early days, he did a lot of work with coagulation, especially with Factor XIII and so on. But his main focus was to do with oncology. His professorship was to do with oncology at University of Bradford. But, yes, we had a haemophilia centre there and the laboratory staff were excellent there, actually, in terms of teaching me about coagulation, et cetera. I mean, I'm really very grateful.
Q. Then in 1981 you were appointed consultant at Bradford; is that right?
A. Well, Professor Turner was taken ill and I had just passed my MRCPath and within two weeks -- we were on holiday and I was informed that he was ill and would I take over. I was the Senior Registrar so, in fact,

I took over as locum consultant but also effectively in charge of the department there, and I would be the locum director of the haemophilia centre as well. But we lost staff. I was a Senior Registrar became locum consultant.
Q. So that, as you described, happened rather suddenly?
A. Very suddenly.
Q. You were only 32 or something --
A. 31 --
Q. 31.
A. -- and it was seven years post qualification. So I was one of the youngest consultants in Yorkshire but treating both haematology and oncology. So I was also treating solid tumours, breast cancers, and so on.
Q. So you suddenly in 1981 are appointed consultant and effectively acting director of the centre?
A. That's right.
Q. Does Professor Turner ever return to his role as director of the centre?
A. Well, he came back for a couple of weeks and then he retired totally and, by that time, I think two years, I was appointed to substantial post in 1982.
Q. So, although it says on your CV "appointed centre director 1982", in fact, you were carrying out that role from 1981?

A. Yes, I was, yes.
Q. You mentioned that you were also carrying out a role in oncology. Can you give us an idea of how much of your working week was divided between your role as an oncologist, haematologist and your haemophilia care in that early period 1981?
A. It was a tough time for me because I was doing too many jobs, basically. There were only two consultants, two of us for a size city of Bradford, you know. I would have said --
Q. Two consultants for in what speciality?
A. One in haematology and I became the haematologist/oncologist. I was then accredited in oncology, which very few people in the country who were both accredited in both specialties, you know, but purely by accident, I think. But in terms of how much time I spent, most of my time, probably 90 per cent of the time, was spent to do with chemotherapy and haematological malignancies and solid tumours. A small amount of time spent with haemophilia care or coagulation, and I think we'll talk probably more about it because coagulation disorders was a very big thing in Bradford but not necessarily haemophiliacs.
Q. So you're split 90/10 in those early years?

A. Possibly.
Q. I understand it's a long time ago, your best estimate in those early years, and did that remain the case through your working life or did that change as the years went by?
A. Well, as years went by, I wanted to give up the oncology because I really did not have formal training. It was an impossible job for anybody to do all that. So we agreed with the Trust and health authority, they were going to appoint a third haematologist but that -- we agreed that that should become an oncologist. So it was the first medical oncologist in Yorkshire was appointed in Bradford, pure medical oncologist, not radiotherapy. So I dropped oncological work and did haematology and the director of the haemophilia centre. But the cost of that was that I was only given four clinical beds for haematology and for haemophilia work. It was grossly inadequate, you know. But, I think, as my story evolves, we started a charity, Annette Fox Leukaemia Fund. We started gathering money, we built a unit which then could also treat both the leukaemias, and so on, but at the same time we could have a place where we could treat people with coagulation disorders. Also at the time we tried to enlist

Dr Minford, Adrian Minford, paediatrician to try and help me to look after the children because I wasn't qualified for that. I had no paediatric training. But we were very lucky because we were able to build up a team, and so on.

Sorry, I'm carrying on a bit.

Q. That's quite all right. Just going back then to when you think you dropped the oncology and you got the oncologist, the third consultant, when do you think that was?

A. Probably I think '84/'85, something like that.

Q. So then you had more time to, spend on the centre than you had before; is that right? That was the idea presumably?

A. I never had enough time, ever, until I retired.

Q. Then, Professor Parapia, you also, in amongst all of that, were carrying out various teaching and academic roles with the Leeds Medical School and with the -- and director between 1991 and 1996 of post-graduate education at Bradford Teaching Hospital?

A. Yes, I tried to -- we tried to get into research. Like I said, I tried to build a team. I built links with the University of Bradford, which is where I got my visiting professorship. I started haemostasis thrombosis unit there as well. One of the things

I think it's often not realised -- it wasn't realised by managers or Health Service or UKHCDO, and so on, Bradford had a large population of Pakistani immigrants, and one of the things about them, including in other places like Birmingham, and so on, was there was a lot of consanguineous marriages, so we had children, and some adults but largely children, who had very rare disorders, disorders that even now haven't been fully recognised.

So although haemophilia may've had a greater impact because of the amount of money we spent, and Haemophilia Society and UKHCDO and so on, but we had a large number of people with bleeding disorders that made up our centre and took up a lot of our time. And from my publications and so on you would have seen that we had rare platelet disorders, we had Factor XIII deficiency. And Dr Minford gratefully -- and protein C deficiency. And Dr Minford gratefully, you know, got into partnership and we produced a lot of research and papers based on that. Which is one of the reasons why I always felt that UK Haemophilia Centres Directors, that we were a big centre, short of resources and staff, but never got the acknowledgement as the Reference Centres did.

So it was one way of getting resources, if you

had been upgraded, you know. But we managed.

Q. Then you continued in those roles until your retirement in 2009?

A. Yes. In between, like I said, I -- you see, one of the important things was to keep our staff. And there was always this pressure that because we were in proximity to Leeds and so on that the senior registrar and the registrar training should be taken away from Bradford. So, you know, we had to build a department so we could retain.

So we did have -- you know, made sure that we were training people, carrying out research. We made sure that the registrars and senior registrars got proper formal training, and they produced papers, et cetera. We tried to get resources, money, and built a ward. My wife was a trustee as well, you know, and we raised money.

But in order to keep our department intact with staff and resources, we had to build links. And so, in the later years, I became one of the sub-deans at Leeds medical school, an honorary senior lecturer, et cetera.

I mean, there's a whole load of appointments that I had. I was Director of Postgraduate Education in Bradford, and then, obviously, I was an examiner at

various colleges and so on.

Q. Then you had your first meeting, that I've been able to find, of the UKHCDO, so annual directors' meeting. You attended that in November 1979. So that is when you were a senior registrar in Leeds and Bradford. Does that sound right to you?

A. Unusual for a senior registrar to have attended the UKHCDO meeting. I can't remember it but if you've got it there it's obviously there, you know.

Q. So there's a record of you attending on November 1979, October 1981, and that's when you've described that you were *de facto* centre director --

A. Yes, that's right.

Q. -- albeit not yet appointed. And then from then on you were a very regular attender. I think there's only one year that I've identified that you missed. Does that sound right?

A. Yes, very important meetings to attend, because that's where we often got our information, you know. I've got all the minutes for every year. But they were so you could meet colleagues as well. You know, very important indeed.

Q. But you never held a role on any of the working party groups. As you've described, you were never a Reference Centre Director, so your attendance was

limited to those annual general meetings?
A. Yes, although after a few years there were working parties for platelet disorders and rare coagulation disorders, and we produced guidelines, but they were not the main workings of the UKHCDO. No, I wasn't an executive or within the inner circle, as one would say.
Q. You very kindly shared some of your papers with the Inquiry, and in there we find minutes of working party groups, Reference Centre Director meetings that you didn't attend but you seemed to have the minutes. Can you recall how you got those minutes?
A. I usually tried to attend all the meetings of the wider UKHCDO, because -- but obviously the UKHCDO Reference Directors' meeting which I couldn't attend.
Q. But you seem to have the minutes. Do you recall how you got the minutes?
A. Well, I presume they must have been sent to me. I think they would have been circulated.
Q. Do you have a recollection of getting regular minutes of meetings of Reference Centre Directors and so on?
A. I tried to get minutes of most meetings because -- we were all desperate for knowledge, to make the best decisions. We needed information. Now, any source of information, whether it's UKHCDO, from pharmaceutical

companies, from regional meetings or lectures, international meetings, we would try and get that information. If it was written, and I kept quite a lot of it -- I still have a lot by the way, you know, that you could have. So, yes, you know, I must have received much of these, you know.
Q. You also mention in your witness statement that there were other committees that you were members of and, in particular, a member of the Regional Haemophilia Group in Yorkshire, and from one of the documents that we'll go to in due course, there's a list of attendees, and I just wonder if you have in recollection yourself of who would attend those meetings?
A. Well, Leeds was the largest centre.
Q. Yes.
A. We were the second largest, in terms of haemophiliacs. But other -- you see, it was a bit complicated because you had the haemophilia centre, then at that time you had associated haemophilia centres. I think the idea was to help the haemophilia centres, so it was like York and I think Harrogate -- Hull was reasonably big, but then you had the associate. Now I can't remember which ones were which. But -- Huddersfield may have been associate. But I really can't tell you how the membership was organised.

Q. So the minutes of this particular meeting suggest that you were there, Dr Swinburne was there, from Leeds, Dr Tovey. I understand he was from the Regional Transfusion Centre?
A. Yes, he was the director of the Regional Transfusion --
Q. Of the Yorkshire Regional Transfusion Centre, is it?
A. That's right, yes.
Q. Dr A Robinson, Angela Robinson, from the Blood Transfusion Service?
A. Yes, that's right.
Q. Was she from the Regional Blood Transfusion Service at that stage?
A. Yes, Regional Transfusion Centre, but she also had slight involvement with paediatrics I think.
Q. Dr Hutchinson?
A. I don't remember him.
Q. Dr Barnard --
A. Dr Barnard, yes, he was a haematologist at St James's Hospital.
Q. And Dr McEvoy?
A. Dr McEvoy was at Harrogate, and he was one of the very senior haematologists. Lot of experience and very wise.
Q. Can you recall whether, in those group meetings,

anybody from Sheffield would attend, because, of course, Sheffield was a Reference Centre, wasn't it?
A. No.
Q. No-one from Sheffield there?
A. No. And Sheffield was always considered a competitor, in terms of the transfusion centres, with Leeds. But no, no, we wouldn't have. That was a different region.
Q. Thinking back to those meetings, it seems from the minutes and documents we've got -- and we'll go to some of them during the course of your evidence -- that the issues that were discussed in that forum were allocation of NHS product from the Regional Blood Transfusion Centre, regional contracting for commercial products, treatment policies and so on. Does that sound right?
A. I think that's a simplification, yes. That's a summary. You're right.
Q. What do you recall -- the forum? What do you recall being discussed at those meetings generally?
A. Well, they discussed what you've just stated, what our requirements were. But I think they could have done better. They could have been more detailed and -- for example, in those minutes it will say what we required and what we were likely to use and what the overall

requirement, but it doesn't actually talk of stock control.

Q. We can come to some of that detail when we look at the documents.

Then, just moving through, as well you were a member of The Haemophilia Society but you never had a role on their Medical Advisory Panel or any other such advisory panel?

A. No, all directors were made members of The Haemophilia Society but I did have a few articles printed in there. I think you've got some of them.

Q. Yes.

A. I mean, we might have had one or two small grants.

Q. Then moving on then to ask you some questions about the facilities and services at the centre itself, and you've already given some evidence in relation to that. I think you described that you only had four beds when you first started?

A. And it got worse. Go on.

Q. What were the facilities like in terms of the physical -- in terms of bed space and where the unit actually -- what centre it actually was when you first came to Bradford in 1978?

A. You see, in terms of haemophilia care, we seemed to concentrate on concentrates and treatment, but

haemophiliacs were patients, you know, and we were -- the haemophilia centres were often their best friends because they spent a lot of time with us and they came to know us.

The facilities in Bradford when I got there in '81 were abysmal, terrible. We used to use cryoprecipitate which was made by the blood bank. They didn't have any physical space where they could actually be treated. And it was really if there was space left over from treating cancers and so on. They might have to be seen in the lab. There was no clinical area one could look at. They would have to come into the laboratory, into my office. The offices were in the laboratory, with the microscopes, you know. We often had to see them there. We often had to see them in chairs outside. We often -- I mean, it was terrible. As they were getting cryoprecipitate they often had to stay in the hospital for a while, you know, a few hours at a time.

They were very disabled. I think that's been mentioned a few times by other directors, how disabled they were. And really the whole thing was awful. They were not being treated like proper human beings. You know, the cancer patients had better facilities. The focus was on malignant -- malignancies, cancers,

more emotive, and it was very, very sad.

Q. You've described how you built a unit. So until the time when you built a unit, was that the position? There was no treatment room, nowhere for anyone with haemophilia to be treated?

A. No, what I had to do, because I couldn't get anywhere with the trust -- they weren't trusts then, were they? They were hospital boards or whatever -- I got health and safety people, and they put a notice up saying that this place wasn't fit to treat people, you know, to look at patients. And I thought that might do the trick because I wasn't getting anywhere. Well, there was Crown immunity at that time. They couldn't have cared less what the health and safety people said. It wasn't the hospital management's worry, about that.

Anyway, after really --

Q. When was that?

A. That would be, like, '84 I think, round about that time. It made me unpopular by the way. I was never popular with managers.

But anyway, they made me a little room with a skylight -- but this was before our unit was built, you know -- and that was a big step in the right direction, because we could put somebody there, give them privacy, you know, counselling, talk to them,

time, et cetera. But that was before we built the unit.

Q. So when do you think you got that room, that treatment room you could use for treatment and counselling?

A. I think it must have been '84/'85, because the unit was built ...

Q. '92?

A. Yes, that was in early 90s. So it was a bonus just to have a place, you know. But I think the overall message is we think of haemophilia with concentrates, et cetera, but we forget that they needed all the other supporting things to help them be treated like normal human beings, you know.

Q. So when you arrived at the centre in '78, were there any joint clinics with dentists or --

A. No.

Q. It was people came in for their haemophilia care and that was it?

A. Nothing, nothing really at all. So when I got appointed, I started recruiting -- remember, we weren't Reference Centre. We weren't given resources. You know, we had to fight from within what the hospitals had, and we were very, very lucky to have some incredibly great people. You know, Adrian Minford, who was never trained as

a haematologist, he helped to take up children and start learning about haemophiliac -- you know, bleeding disorders. We got a community dental surgeon, Hugh McCarthy. He wasn't getting paid extra and so on, but he joined us and he started -- they had had no dental care. Haemophiliacs didn't have any dental care because dentists wouldn't touch them with a bargepole. They wouldn't come anywhere near. And so Hugh McCarthy was a community dental officer who took them as part of his job. You know, incredible.

Then we had Sister Pauline Sharp, who was a dermatology sister, but when I had two beds on her ward she started taking interest in haemophilia, and we got her gradually trained up to become a nurse specialist. Again, no extra resources, again from within our own resources.

Then we had Brian Hamilton, orthopaedic surgeon. Again, he gave up his own time to come to our clinics and started looking at the joints, et cetera.

Then we did get one resource from social services, which was they managed to give some time for a social worker who was trained as a counsellor. So I think we were the first in Yorkshire to have somebody who was sort of dedicated doing the social aspects, you know, and so on. But much, much later

when we had the unit, obviously, the leukaemia fund started funding various things that the haemophiliacs could use.

But yes, we built up a team and started clinics, dedicated clinics, from again within our own resources, otherwise the haemophiliacs used to come to a general haematological -- there may be 50 to 100 patients and they would be at the end of the queue, you know, because we had to decide what blood types they had as well, you know. So it was quite a struggle.

Q. Henry, can we have up HSOC002093, page 8. HSOC002093. That's not got enough digits in it. It must be 000. HSOC0020293.

Is that the right -- you got that? In fact, can we show page 1 first and go over to page 2. This is a publication, I think, it says at the bottom there papers taken from an International Symposium on HIV, Haemophilia and Community held at Bradford University on 23 and 24 April 1987. Then if we go to page 7, we can see a paper by you, *"Advances in Haemophilia Care"*. If we go over to page 8, there's a diagram on the right-hand side, we can just go into there and you have set out the services in 1987 at the centre and you've got there the haemophilia sister and that's

Pauline Sharp, is it?

A. That's right.

Q. You have described a consultant haematologist and Senior Registrar, so that's obviously you and a Senior Registrar, and then the consultant orthopaedic surgeon and a physiotherapist, at that stage.

A. That's right.

Q. Social worker and counselling, and you have described -- I think in your witness statement you say you had a social worker/counsellor for a few years?

A. That's right, Andrea Bridge.

Q. From another document that you provided to the Inquiry, it looks like you were about to get the social worker at the end of 1985; does that sound about the right sort of time?

A. Yes.

Q. Then you've described the dental surgeon and a Dr Minford, the paediatrician. Can you recall -- we know that was all in place by April 1987. You arrive in 1981, centre director in 1982; can you recall how long it took you to get up to this service?

A. I can't give you exact times but it was like completing a jigsaw, you know, bit by bit whatever we could get. These were not working exclusively for the centre, because they had their own jobs, and so on.

By the way, I didn't mention but we had a very good physiotherapist who from their department who started taking an interest as well.

But what we had here was -- the big talk then was comprehensive care. So instead of Reference Centres they should have called them Comprehensive Care Centres. Reference means you refer, don't you? You get advice, et cetera, but even the Reference Centres didn't have this model and we were putting this forward that this is how they should be treating, not exclusively, because you couldn't do that for 40 or even 100 people with bleeding disorders. But this was what I would have called an ideal model, which we were trying to today attain and which we did largely, purely because of goodwill from a lot of very good people in the hospital. But this was what we had set up.

The conference, really, was to put this forward. I think there's some other papers in there where, I think, Professor Tuddenham attended that as well and Professor Zimmerman from La Jolla in California, who is a very, very great man, great scientist. I think you might come to that because not everybody had this journal, by the way. It's a Bradford-printed journal.

Q. We have a statement from Dr Minford and in his

statement he says that, as you've described, he came to work with you. He was a consultant paediatrician, no training in haematology, but he came to work with you to help you in your clinics with the children, and he describes having joint clinics with you once a month from between about 1983 to about 1986 and thereafter he then went and took his children patients to a separate out-patient clinic where he managed them on his own.

Does that accord with your recollection of how you divided care for the children with haemophilia at that time?

A. Absolutely. You know that would be correct. But, you know, it's, a great commendation that here's a paediatrician that takes on a completely new area of work, which is full of controversy and it's amazing. Even until recently he has been travelling the world and giving talks on Protein C deficiency, et cetera, you know. His interest has been maintained. A great man.

Q. So how frequently did you have, in that early 1980s period how frequently were you having clinics for adults; was that once a month, as well?

A. The comprehensive clinic was once month. Now, we used to see people all the time because the way I worked

was I was accessible to any patient at any time in my office laboratory, you know, where I was. I had an open door policy, literally accessible and accessible on the phone seven days a week. You know, it was open -- that was -- but haematology clinics we had twice a week, which they had access to as well, particularly on Monday afternoons. But the comprehensive care model was once a month with all these people trying to get involved on that particular day.

Q. So if people needed to come and have treatment outside those clinic times, where would they come and how would they be treated?

A. They would ring my secretaries or the laboratory, quite often the laboratory, because the laboratory prepared the material, you know the blood bank in our hospital. They would inform the doctor on call or me, but often the doctor on call. Later on, Sister Sharp became nurse specialist, so the calls also went through her. I can't remember now the dates and times, but we were very accessible very easily.

But having a good organisation, you know, good communication meant that the time it took for a haemophiliac to be treated was shorter and shorter and better. Something I don't think we've talked in

the directors -- you know, you've interviewed before. If somebody had a bleed the damage done waiting two hours, three hours before they got their cryoprecipitate or treatment or whatever, that causes damage. It causes pain, discomfort. So the sooner they get treatment, the better it is and home treatment was great for that, you know. There was no time wasted before they got treated for a bleed, you know.

Q. So if they needed urgent treatment during the working week or during the day, they could make a phone call and come on to -- what you describe there, really there was no area for them to come to but they could come to the laboratory or your office?

A. Out-of-hours they would have to go to the ward.

Q. The haematology ward?

A. Yes.

Q. If they needed treatment, you know, in the middle of the night, for example, would they have to go to A&E?

A. No. That's something I think it was terrible because that used to happen and often accidents mistakes in treating people happened because haemophiliacs went to A&E. I think that was a dangerous area for them because they would be looked at initially by people who had no knowledge of haemophilia and haemophiliac

care.

But, I mean, if they did turn up at A&E the whole message there was call the haematologist on call, call the doctor on call, you know.

Q. So patients would turn up at the haematology ward in the middle of the night, would they, if they needed treatment --

A. We tried to -- we tried to help them not go to A&E.

Q. We looked in 1987 there was you and a Senior Registrar and, of course, Dr Minford providing paediatric care. How did the on-call rota work then, were there quite a few people delivering care to people with haemophilia outside office hours, or was it just split between the two of you?

A. You see, fortunately, as we developed into a proper training, et cetera, we had a few middle-grade doctors that could be on call, first on call. We tried not to use House Officers, which often happens even in Reference Centres, in big centres and so on. House Officers were the least trained, but we had middle-grade, SHOs, Registrars and Senior Registrars were better trained. So that was accessible to the patients with bleeding disorders and then we were there, obviously, I was there. I couldn't be first on call all the time but I was always there, even on

holidays, at Christmas time. It's stressful that.
Q. So there might be -- you and your Senior Registrar, obviously, couldn't cover all the on-calls?
A. Registrars and Senior House Officers, yes.
Q. Who would cover. Did you have any written treatment guidelines, at any stage, that they could refer to for when patients came in and you weren't there?
A. Always, but not only that, we made sure that the laboratory -- so when they asked for blood products from the laboratory, who prepared the products. The laboratory had a guideline and we had such good staff that they actually came to know the patients and they had a book which they would look up, and each patient we had written down what sort of treatment they should get, what products.

I noticed from the previous directors you've had -- we tried not to mix the products because if something went wrong at least we would know which batch or what was happening there. We tried not to give each person each patient different batches from different companies. But, yes, it was always written down. It was protocolised and, obviously, UKHCDO was very helpful in there, because they did produce guidelines, and we tried to stick to UKHCDO guidelines, as far as we could.

your first treatment protocol?
A. Not only concentrates, when we had DDAVP, you know. That came on the scene. But that was also different, we had different choices between different concentrates.
Q. Again, so that would mean that you would have to have a protocol. Where would that protocol have been kept; would it have been on the ward?
A. Well, in the laboratory, very important, because they checked -- whenever anybody needed treatment we made sure that they knew -- ward definitely and obviously that the doctors were informed. They were well circulated, you know. If in doubt they rang me, you know.
Q. Do you know where they were kept? No protocols have been disclosed to the Inquiry. Do you know what could have happened to them or where we might find copies of those now?
A. Very difficult, but I think you have from the documents from me, that UKHCDO it does set out a protocol -- a recommendation not protocol. Protocol is the wrong word, recommendations. Those were the recommendations that would have been given. You've got minutes of the regional meetings where also we state what should be used and we adhered to it, you

Q. Can you remember when you drew up your first protocol or treatment guidelines for other members of staff to refer to when they were providing treatment?
A. Now, it's quite interesting in that when I got there -- and I have a conscious about this actually -- so when I got there in '81, they were using cryoprecipitate almost exclusively but because we were using cryoprecipitate there were a lot of centres that were thinking that Bradford was an inferior place that didn't keep up with the times, you know, and a lot of patients also felt that we were not keeping up with the times because they were well informed from society, and so on, and from companies by the way. They would go to other centres, and so on.

I have a little problem myself because I was the first one who really to order the commercial products. Now, cryoprecipitate wasn't the best treatment but, as soon as we started having a choice of treatments, we had to have a protocol and then, obviously, we needed protocol because mild haemophiliacs and von Willebrand's, and so on, the first call would be on DDAVP, you know. It wouldn't be on --
Q. So you had to have a protocol when you had a choice of treatment. So, as soon as concentrates came on the scene, you think that's when you would have drawn up

know.
Q. We can come to those in due course.

So I think you were describing a book that the laboratory clinicians could refer to when patients came to get treatment, and in your witness statement you have said that there were effectively two sets of notes: you had the hospital notes and then you had your own records of treatment that you kept.

Your own records, is that what you're referring to when you describe the book?
A. No, no. The blood bank had a book with each patient's name and what products they were getting, and also at the top it would say what the recommendation was. That was one.

The hospital case notes, which are an absolute mess, they were hospital notes, like all other notes. If you wanted the hospital notes to look up treatment, et cetera, it could take two hours to two days. So we kept our own what we called "green cards", and they were kept in my room in a filing cabinet that anybody could come and pick it out and that actually mentioned what treatment they should get and the record of what they were getting and also the clinical notes were written on it. That was accessible almost immediately, okay.

So there are three different areas.
Q. Was everything that was on the green card also in the hospital notes?
A. Well, if anybody was seen as an emergency or something you wrote in the green card, it may or may not have gone into the main case notes. But if they were seen in the clinic or -- then there was always a letter, there was always a letter in the case notes.
Q. Was the green card system the system in place until you retired in 2009?
A. Yes, it was. Yes. But now I think they have computerised everything.
Q. So when you left in 2009, your office still had that filing cabinet with that information in it?
A. That's right. I'm not sure what records were destroyed and what weren't but I think there's a lot of material that's -- can't find it.
Q. We'll talk about home treatment in a little while but just while we're on records, when people were on home treatment, what was the expectation of them in terms of keeping records and sending you information about their treatment?
A. If they didn't keep records they would not get home treatment. So what -- we kept records of what was issued but we kept records of what they brought back,

otherwise they wouldn't get the next issue. That means they had to note down the bleeds they had and why they had the Factor VIII. And they had to bring back the needles. You know, they were given appropriate containers. So all those records were kept just as if they were being treated in hospital.
Q. That would have been entered onto the green card system?
A. That would have been entered in the blood bank records, because they couldn't exchange. So it was the blood bank staff who issued new bottles and home treatment packs of needles or whatever they needed.
Q. I am just going to ask you some questions now about patient numbers, and treatment policies over those years in the early 1980s.
Before I do, can I just ask whether or not you recall whether or not you were given any guidance or training by Professor Turner when you were working with him about treatment policies?
A. I don't think he had treatment policies except that they were using cryoprecipitate almost exclusively. Very little commercial product was used. And I think the commercial product that I see on the returns, which didn't know until I saw those returns, may have been -- haemophiliacs were able to travel once they

could carry Factor VIII with them. You know, they were unable to travel otherwise. And I think sometimes if they were in Bradford, they would bring the bottles and get treated, and that would be recorded. But Professor -- he was quite old fashioned and he believed cryoprecipitate was okay.
Q. So shall we look at -- we'll look at the 1976 return. So this is before you arrive but it's under his directorship.
Henry, it's HCDO0000037_002.
We can see there, 1976, Professor Turner, total number of people with haemophilia treated during the year, 18. And then he's given primarily cryoprecipitate and he's given a small amount of Kryobulin.
That was more or less the picture, was it, when you arrived in 1978?
A. Now this Kryobulin may have been somebody -- a traveller, a tourist, you know, somebody going through Bradford --
Q. So you think --
A. -- getting his own material.
Q. So you think that's unlikely that that would have been prescribed by Professor Turner?
A. Completely. Very unlikely. Actually, he would not

have known what Kryobulin was.
Q. We don't have the returns up to 1981 but are you pretty confident then that up to the time when you stepped in as acting director, it would have been primarily cryoprecipitate?
A. Absolutely.
Q. And then when you took over in 1981, before you were appointed director in 1982, were you able to make any changes to the treatment policy at that stage or did you feel you had to wait until you were appointed director?
A. Well, this is the bit that I've tried to remember, whether -- because there was a lot of pressure to change, you know.
So I can't recall but I was responsible for ordering the first concentrate. And whether I did it through pharmacy or Blood Transfusion Service I'm not sure. But it may have been in 1982, I think, that may have happened.
Q. Can we look then at the 1982 return.
Henry, that's at PARA0000003.
A. See, by this time there was a large amount of commercial factor being used in the country. Actually, there was more commercial products being used than NHS material, you know. So we were quite

late on the scene, really.
Q. PARA0000003. That's definitely the right -- can you access PARA0000002.
(Pause)
We don't have that document, so we may have to come back to that.
I note the time, sir. I wonder whether now is a good --
SIR BRIAN LANGSTAFF: It might be convenient if we took our morning break now so that the document can be located, and any other documents that you might want to refer to you can just check are on the system.
MS SCOTT: Thank you.
SIR BRIAN LANGSTAFF: Professor, the rule that we operate is that when you are giving evidence you can't talk during a break of any sort, any length, to anyone at all about your evidence. You can talk about anything else you like but not about your evidence, either what you have said or what you think you might be asked to say. Can I ask you to observe that, please.
We will have a break in the morning. It's always a lengthy-ish break because we have to make sure that people keep social distance, and we'll be back in just under half an hour, 11.25.
So 11.25 if you, please.

(10.57 am)
(A short break)
(11.25 am)
MS SCOTT: I think, Henry, you now have PARA0000003. This is the 1982 return. You can see you're noted as centre director. You treated 22 patients with haemophilia A that year and five with von Willebrand's disease. We can see there that your treatments are made up of NHS Factor VIII, a small amount of Factor VIII and Kryobulin for those with haemophilia A and then with cryoprecipitate for those with von Willebrand's.
So that was the new policy, treatment policy, that you'd brought in as centre director to move away from cryoprecipitate to factor concentrates.
SIR BRIAN LANGSTAFF: It looks as though there's home treatment, which is largely a ratio of about 4 to 1 Factor VIII compared to NHS; is that right?
A. Absolutely. I think this would be right, sir. I would be responsible for ordering the commercial products and I would have been responsible for introducing home treatment.
SIR BRIAN LANGSTAFF: Before this, before you had factor concentrate, did you have home treatment?
A. No, not really. I can't remember. I don't think so,

no. I don't think we used cryoprecipitate as home treatment.
MS SCOTT: Do you recall whether, at this stage, you had a prophylaxis treatment programme?
A. No, I think prophylaxis came a bit later.
Q. Can you recall when that came in?
A. You see -- once you had home treatment, patients quite often actually gave it prophylactically, particularly if they felt they were going to play a football match or do something that could make them bleed, and we were quite happy for that. You know -- I mean, I had one patient who did karate, against my advice by the way, he was a black belt. I said you mustn't do that. But he would give himself a shot, you know, before doing. I think, in a sense, we had started and once you started home treatment -- so if they were having to give themselves injections three times a week, say, because of three bleeds on a regular basis, you might as well give it three times regularly rather than wait for a bleed.
So I think there is a slight overlap. But the formal prophylaxis, if one did that, you had to see how much of material we had, you know, how much we could afford. Also the home packs. You know, it was important to know how the home packs were organised,

and one would have to be very careful about abuse as well, because prophylaxis wasn't about total replacement. You know, it was about stopping to get a bleed.
Q. Do you recall when the formal programme came in?
A. Sorry, I can't remember because, like I said, there is an overlap between the two.
Q. Just looking down at other materials --
SIR BRIAN LANGSTAFF: Just a moment before you do, you described a process of prophylaxis *ad hoc*, somebody going to do karate, play football. When the person on home treatment came back to the hospital, with their record of what they had used for the bleeds they had, of course they wouldn't have had a bleed on that occasion.
A. No, and we didn't examine the records that closely.
SIR BRIAN LANGSTAFF: You didn't?
A. No, because I think it's a question of if, on balance, they were well, surely I'm happy with that, as long as they didn't use it excessively, you know. We didn't police it that closely, as long as they didn't go beyond a reasonable use, you know.
SIR BRIAN LANGSTAFF: So within limits it was expected they might use it?
A. Absolutely, yes. I mean, it was inevitable, wasn't

it, once you got the material at home, you know?

SIR BRIAN LANGSTAFF: Particularly, I suspect, if they are young adults.

A. Absolutely. One of the things about haemophilia care was that you wanted them to be fit. You wanted them to exercise, you wanted them to have as far as normal lives as possible. The better fitness they had, the less bleeds they had. So we didn't mind at all as long as it was for the right reasons, you know.

SIR BRIAN LANGSTAFF: Thank you.

MS SCOTT: Just looking down at the bottom of that page at other materials, if you had been treating with DDAVP or tranexamic acid, would you have expected to have recorded that there?

A. Yes, we would, and the reason why it's not recorded, I suspect, is because these are records from the blood bank. DDAVP is a pharmaceutical product that would not be kept recorded in the blood bank. So the returns were largely prepared by staff in the laboratory.

Q. So this doesn't necessarily tell us that you didn't use DDAVP?

A. Yes, that's right. Once it was available we did use it but because the returns were not -- were done by the laboratory staff, blood bank staff, it may not

have been recorded.

Q. Henry, could we have PARA0000002, please. This, as I understand it, is a survey of European haemophilia centres and if we go to the second page, Henry, to the bottom, we see it says there:

"Please return to [Professor Bloom] as soon as possible before 20 January 1984."

Then if we go back to the first page, the first question is to ask how many patients you treated each year at your centre, eg 1982. Then it's question 2:

"During the last four years what products have you used ..."

You set out there the products that you've used presumably during your time at the Bradford centre and we don't see any record there of DDAVP or tranexamic acid. Looking at that, do you think that, by the time you filled this in, which seems to be probably the end of 1983/beginning of 1984, that actually you weren't using that product at that time?

A. I can't remember when DDAVP came into use but if it was there, we would have used it, you know, undoubtedly Tranexamic acid we were probably one of the first and used it quite commonly but, I think -- I don't know. We may have been concentrating on concentrates and cryo and NHS, I can't remember.

Q. So your recollection is you did use it, even though it's not recorded in any of the --

A. When it was available, yes. I'm trying to think.

SIR BRIAN LANGSTAFF: It would, I think, have been available from 1978 onwards.

A. Then we would have used it, yes. We would have used it, yes. But, like I said, because it was recorded via pharmacy, so it would have been on the green cards but not in the laboratory. No, we would have used it because we tried to avoid, as you know -- so in von Willebrand's and mild haemophilia we used DDAVP.

MS SCOTT: Henry, can we have HCDO0000228_002.

A. I think, I suspect when I filled that in I probably had in mind about blood products rather than thinking of pharmaceutical products, you know.

Q. This is the 1983 return and we can see here, again, the pattern continues that you're treating, both at home and in hospital with a mixture of NHS factor and commercial factor, here Factor VIII and Kryobulin for those with haemophilia A, and for those with von Willebrand's you're treating, no home treatment, just cryoprecipitate in hospital.

Can I just ask you what your treatment policies were at that time in terms of deciding who had NHS factor and who had commercial factor?

A. I mean, we followed the UKHCDO guidelines. We tried to keep to one product all the time but something that tipped us towards the commercial was home treatment. The home treatment packs were far better. NHS packs, if I remember, had to be made up. They didn't come in ready-made packs. But the commercial were all ready in a nice little box with the needle and everything.

The commercial products were far more soluble because they were purer than the NHS, the intermediate. So that may have tipped us because you needed less water to mix.

Q. What was the advantage of needing less water; what was that advantage?

A. Well, you needed everything smaller so it was more soluble, less water to mix the product, less to draw up, less to inject, you know, rather than a bigger volume. This is all from memory. I think that may explain why we got a lot more for home treatment, the commercial product, than using the NHS.

Now, in terms of -- we would have followed UKHCDO guidelines so, for people who weren't exposed to commercial, we would have tried to use NHS. If they had been using NHS, we would have tried to use NHS but for home treatment -- and these are for severe ones. Because home treatment, by the way, was not

given for mild ones; they were for very severe haemophiliacs. That may explain why we got more commercial for home treatments.

Q. So before UKHCDO provided any recommendations, would you have chosen between NHS factor and commercial factor, simply on the convenience of the home treatment packs, as you have described?

A. No, no, I don't think so. I think from the documents I've given, you'll see that time and time again I said we prefer NHS products, you know, to commercial. So I think if they came to hospital it's very likely that they had NHS. So the infrequent users would have probably had NHS.

I think that's as far as -- but we followed the guidelines, you know.

Q. So there's quite a lot of predominantly commercial factor being used in hospital there, rather than NHS.

A. Yes.

Q. Does that assist at all in identifying what the policy was at that stage? I think in your witness statement you've said that you had -- you didn't have any problems with supply of NHS Factor VIII over these years, you had sufficient supply?

A. Always.

Q. Always.

A. But I'm sure you'll want to talk about that later.

Q. Yes. But your recollection is that you always had enough NHS supply?

A. Yes, but --

Q. So the reason for putting people on commercial was because it was more convenient?

A. Yes, but also maybe I can explain about the NHS. When we ordered NHS material it was always available but the official line from the Blood Transfusion Service and official line nationally, and from UKHCDO, that there wasn't enough NHS material. So we had to use it -- you know, we had to be aware that we didn't use up all the NHS material from the region. So there had to be balance to give other centres a chance to use in proportion, you know, that we used NHS material and we used commercial, but without just using NHS all the time because that wouldn't have been fair.

Q. So when you say you never had any problems with NHS supply, it wasn't that you could have said to the Blood Transfusion Centre: I want enough NHS product to meet all my treatment needs, all my patients' treatment needs?

A. That wouldn't have been allowed --

Q. Right.

A. -- because, you've seen the regional guidelines as

well. What I didn't know, and it baffles me actually it still baffles me, is we could have used more NHS if people had given us like stock control and said "Look we've got this much lying here, yes, you can have a bit more, you can use more". It was never like that; you ordered and you got. So we had to use our own balance, you know, of how much to use and obviously one didn't want to go predominantly NHS when you didn't know that there were other centres involved in the region as well.

Q. So did you ever -- was there ever a circumstance where you said to the regional Blood Transfusion Centre I want more NHS and they said "No, actually all you can have is this"; you always got what you asked for, did you?

A. Yes, we did, yes. I mean, that's what I meant by -- we had never trouble -- we were never denied NHS products from transfusion centre. On the other hand, we never knew how much they had that they could spare.

Q. But you didn't feel, as a matter of fairness to other centres, that you could ask for more than you had asked for because then there wouldn't be any for anybody else?

A. Absolutely. It just makes me wonder that -- why weren't there sort of regular information about stock

control and what was available and what wasn't and what it was costing and what the budgets were, how much was affordable, because you were paying more for commercial products than NHS. At the end of the day, and I think this what all the directors would say, we were trying to use the best product, that we thought was the best product in the interest of the patient and that also meant what was also easier to administer, easier to obtain, et cetera, you know.

Q. So just trying to think back about what the treatment policies were, you said NHS was the best product on some levels?

A. On some levels, yes.

Q. Commercial product was the best product for other factors, like convenience?

A. Yes, but also, because I don't know the exact dates and so on, the commercial products always had an edge over scientific -- you know, on producing a better product while NHS were always following whatever commercial companies first achieved like the heat treatment and raising the level of the heat, you know, the purer Factor VIII, et cetera. So we would always be looking to see what was the most convenient and the best at the time, you know.

I mean, it's very sad, and I think you probably

want to discuss this, why couldn't NHS keep up commercially, you know, as a commercial organisation? Because it was not a commercial organisation, you know.

Q. So do you have a clear recollection of the basis upon which you gave NHS concentrate to some patients and commercial to others in that 1981, 1982, 1983 period?

A. I really couldn't go into detail. I can't remember what exact -- but it would have been on clinical situations and need, you know.

Q. When you say "clinical situations", what do you mean by that?

A. Well, we've mentioned about home treatment. For a clinical situation, if somebody was bleeding three or four times a week, then it's better for him to treat it at home, you know, and that obviously led on to prophylaxis. And then it led on to getting, saying, well, we should attain a higher level of Factor VIII. But that's another question.

I honestly can't remember details of how exactly but we did follow UKHCDO guidelines, you know.

Q. We can come on to that.

SIR BRIAN LANGSTAFF: Just before we leave this page, I wonder if I can just go back to your answers about preferring commercial concentrate for home use? If we

look at the figures on the sheet, if we just have a quick look, it looks broadly as though the same total amount of units were used in hospital as were at home, broadly. It comes to about 290-odd units in both. But there's rather more NHS used at home proportionately than in hospital.

So at this stage it may have been transitional?

A. I think it's transitional because NHS would have gone down and commercial would have gone up.

SIR BRIAN LANGSTAFF: So the next year we should see the total use for home treatment of NHS would be rather less proportionately and that commercial rather more?

A. Probably, but we also felt that we should try and keep people on the same product, as far as we could, because then you would know about viral transmissions and about batches.

SIR BRIAN LANGSTAFF: So the same product would be either NHS or commercial, would it?

A. I mean, if you ask me detail I really can't remember, you know, the exact circumstances. But I can tell you as a matter of principle, you know.

SIR BRIAN LANGSTAFF: As a matter of principle it would seem to follow that if someone had received Armour Factorate, for instance, in hospital they would get it at home and vice versa.

A. Quite possibly, yes, absolutely.

SIR BRIAN LANGSTAFF: Well, it follows. If the principle was keeping them on the same, that must follow, mustn't it?

A. Yes, but also we would have to look at the stocks in the blood bank. So a clinical situation arises and there's also stock control in our own blood bank.

SIR BRIAN LANGSTAFF: So there may have been occasions when you weren't able to do it?

A. I honestly couldn't remember but it's not simple. You know, you treat patients as a clinical situation arises, you know.

SIR BRIAN LANGSTAFF: Yes.

A. The overall principle was try and keep them on the same. There's no doubt that the commercial packs, et cetera -- for children particularly, you know, it's -- their home packs were so well done, you know, that they must have done a lot of customer feedback and, obviously, these pharmaceutical companies were international and they had to produce competitive products, you know, competitive packs, competitive everything really, which NHS didn't have to, BPL.

MS SCOTT: In your statement you say that initially you were responsible for selecting blood products for the centre and then at some point that moved into regional

contracting; is that right?

A. Yes. Well -- or, the other way. There was regional contracting and we fed in what we wanted.

Q. So there wasn't a time when you were ordering your own blood products for your centre, it was always regional contracting?

A. When I first started using commercial, the first time, I did order it through pharmacy and I think that was ignorance, actually, that was my naiveté, because really that should have gone via transfusion. But it was only a small amount. It was almost like experimental -- I think it was 10,000 units, which is very, very small.

Q. Is it right that you ordered or you were responsible for the prescribing of all the products, even for the paediatric clinic, certainly up until sort of 1986?

A. I think it's better to put it that I was -- as a director I was accountable for that, rather than ordering it, because obviously ordering and using on a daily -- minute-to-minute -- it's a decision -- it's a clinical decision made by the doctor or nurse looking at the patient, you know. But yes, I was the director.

Q. The decisions, in terms of the decision that you -- the input that the centre had, if I can put it that

way, into the regional contracting arrangements for the supply of blood products, that was your job. It wasn't something that Dr Minford got involved with?

A. No, it was my job entirely. My responsibility.

Q. Can we look then at, Henry, PARA0000015.

This is a letter from Dr Swinburne to you, dated 7 July 1983, and she says:

"I have discussed the supply of Factor VIII and related products with Dr Tovey."

So he is from the Regional Blood Transfusion Centre.

"In the light of the discussions we had had about AIDS, he and Dr Rajah have agreed to look into the question of Cryoprecipitate and to maintain the supply."

I'm going to come back and ask you some questions about that in due course. There's a second paragraph I just want to draw your attention to now:

"Dr Tovey would like to know predicted requirement for 1984/85, and suggested Suppliers towards the end of September; following this he will make recommendations to the RHA and they will ask for tenders. This arrangement worked [well] last year, and we are lucky to be one of the regions which, so far, has had an unrestricted supply."

So, there, am I right to understand that "so far, has had an unrestricted supply" is talking, in fact about NHS product or is she there talking about commercial product?

A. I don't know. Dr Tovey was the head of the blood bank, the Regional Blood Transfusion Centre. Like I said, I never -- there are documents that you have where it is mentioned that if he used exclusively commercial products -- NHS products, there wouldn't be enough for the region, but I never saw the actual figures. Now this is '84/'85, when I think -- I think that may have been a time when NHS was producing a lot more factor. I think there was a time when it was reaching self-sufficiency. But I couldn't tell you the detail.

Q. What is suggested here is that the process is that the directors suggest commercial suppliers to Dr Tovey, he then makes recommendations to the Regional Health Authority, and then the Regional Health Authority deal with the tendering process. Does that accord with your recollection?

A. That's how the system worked, yes, but I think the practice that they got from tendering, I think some other directors have mentioned, you could actually get it cheaper by doing it, but I mean, it's through the

tender, regional tender. Yes, regional.

Q. Then if we look at PARA0000010, we can see in that last big paragraph:

"For the reasons stated before ..."

This is a letter from you to Dr Swinburne in July 1983, so the year before.

"... I would be grateful if Cutter laboratories were considered as one of the suppliers."

So it seems to be you having a discussion with Dr Swinburne about who should be put forward as one of the potential suppliers to Dr Tovey, and you say:

"It is important that there should be flexibility in choosing various commercial firms and the Haemophilia Centre Directors should not be excluded from showing their preferences."

Can you recall why you had a preference for Cutter at that stage?

A. I didn't. I think the principle was we shouldn't have exclusive contracts with one commercial company. Competition is good because that reduced the prices. But there was also the question of flexibility, that while we were treating in here, you found that one product, say, had showed a virus or infections or something, we could remove it and still have an option from another company. But other than that, there was

no reason for choosing one over the other. It could have been any.

Q. We'll see that, I think, in the next document, which is PARA0000020.

This is a letter from Dr Swinburne to Dr Tovey, so this seems to be at the point where the tenders have come back in. And we look -- there she sets out the requirement for product, and she mentions another TV programme on AIDS:

"... some reluctance to use ... commercial Factor VIII by a few patients, but in general the policy is unchanged."

And then she goes on to say:

"I have had quotations from Armour, Immuno, and Alpha ..."

So it seems that the quotations were coming directly to Dr Swinburne. Do you recall that?

A. Well, it should have been through Dr Tovey and then to Dr Swinburne, because they were both in Leeds and Leeds was the bigger centre. So they would have -- you can see from the -- St James's using nearly 3.5 million units while we were using 800,000 units. So they would have the bigger say. And they were using more commercial up to that period than NHS, while we were probably half and half, around abouts.

Q. Would she have discussed -- I mean, she cc'd you into this correspondence. Would she have discussed the choice of suppliers? She then goes on to make the choice of supplier with Cutter -- sorry:

"... continue using Armour as the main supplier with Cutter ... as backup."

Should she have discussed that with you?

A. No.

Q. So that's a decision she made on her own for the region?

A. Yes, on the basis of the information we gave, obviously. You know, we gave her our views and -- but she would have had to look at the region, not just Bradford, you know.

Q. So she is making -- what looks like the only consideration she's giving to which product is on price, and that reflects what you have just said to us, that it could be any of them. They were much of the same -- much of a muchness. Was that the view at that stage?

A. I think if you negotiated individually with companies you could reduce the price, but obviously this is a regional contract. But Dr Swinburne or Dr Tovey would have had to look at what Harrogate, York and Hull had to say, as well as Huddersfield. You know,

that's nearly a million units there, same amount as Bradford. So I don't know what their preferences were, what they said, you know.

Q. Was price -- were there any other factors that you took into account or that you were aware that Dr Swinburne took into account when deciding between different commercial companies, different pharmaceutical companies for this contract?

A. Well, I was very fearful, as time went on, that any of these commercial companies could come up with a problem. Which they did. You know, as we found out, history has shown us. So it was a good thing not to put all your eggs in one basket.

We were desperate for knowledge, absolutely desperate. And I think I've said in my response, you know, to the questions, commercial companies the reps would come and see us and we would get information from them. The BPL, you would hardly see them, and I used to complain, I've actually put formal complaints: why aren't we seeing them? Because I want information about the BPL -- more about the BPL products.

Obviously, we had input from UKHCDO and so on and what we saw in journals, in the various communications -- and I've given you a bundle.

I think the commercial companies were probably about the same but we were fearful that things could go wrong, you know. At that time it was very difficult but at least we had a choice here, you know.

Q. So when commercial companies used to come and see you or when you were considering at the point where you're working out which pharmaceutical company to award the contract to, do you recall getting any information about things like where their donor sites were or who these companies were getting their blood donations from?

A. I think there's a letter and you might have got it already is that when I ordered my first Factor VIII I wanted to have reassurances about the donors and the answer they gave is very simple: it's they're following the American FDA, whatever guidance on the donors. But, yes, that would be a question and in all the things, the big bundle, I've given you there's something from Cutter, for example, in the promotional. The answer is, yes, we did look at it but what they produced was for selling their product.

Q. Yes.

A. You know, how do we know what actually happens? But we do know now because we've had various television series and investigations, and so on.

Q. So your recollection is that you were asking those questions --

A. All the time.

Q. -- you were getting information back from the pharmaceutical companies addressing those issues?

A. "Addressing" may be a bit strong but we were certainly being told that they conform to whatever American standards had been set for donors and they varied, you know, they changed all the time.

Q. What you're saying is: you know, how did we know whether or not that was true or not; they were selling us a product?

A. You see, you have to assume that there's a lot of truth in that because they were licensed. A lot of the products we used were licensed. I tried not to use unlicensed product unless the evidence was strong enough to say that, yes, it's a safer product, use it on a named patient basis. If it was a licensed product it would have gone through the procedure to get the licences and they were probably tougher in America than they were in Britain, you know. Things were moving so fast. We were desperate for real knowledge, truthful knowledge, the truth, and it was -- it only came forward much later, sadly, you know.

Q. So you, at that stage, were having to rely on the fact that the Licensing Authorities must have done their due diligence, because you weren't in a position to do it yourself?

A. No, and we obviously listened to what UKHCDO directors said and they varied in their opinions and their usage. But they were people we obviously listened to very carefully and that was the great advantage to going to the meetings, international meetings and UKHCDO, that you listen to some people, and very difficult to say one product was better than the other.

Q. In those UKHCDO annual meetings, was there discussion about one product over another?

A. Not debate, as such, about one product or other but you could get a very strong on what they were saying in the guidelines, for example, or in their returns. And you talked to people. I mean, the main thing -- the good thing about all these meetings often is you meet your peers, you talk about it, and so on, but you didn't get a clear -- they gave recommendations but they did not give instructions -- I think that's been mentioned a few times -- the UKHCDO.

Q. Yes. So the early recommendations from the UKHCDO don't mention one product over another.

A. No, and they varied a lot, didn't they, because you had Professor Bloom at one time and in his centre he used commercial products then you had Charles Rizza very much in favour of NHS products, you know, and then there was St Thomas', that used exclusively commercial products. So you couldn't get a sort of definite idea from the Reference Centre Directors. But you certainly could get a feeling, not the Reference Centre Director meetings but there were other meetings where you always had pharmaceutical companies with their stands and, you know, information and they produced printed information for people to look at. We were desperate for knowledge, we were desperate for guidance and the most important thing is we were desperate for leadership, which I don't think we ever got properly, either from the Government or UKHCDO or whatever, in difficult area.

Q. You mentioned just now in your evidence that you got an idea of what the Reference Centre Directors favoured in terms of product from their returns. Did you see their Oxford returns?

A. We had summaries of their Oxford returns, yes, because I think -- yes, we could see what proportions were being used overall but they were never complete because there were some centres that never gave in,

that didn't want to give their returns. I don't know for what reason but they did not want them to be made public.

I'm saying a lot of this from memory, you know. It's going back --

Q. It's a long time ago.

A. Yes.

Q. In terms of just going then back to sort of logistics, in terms of the regional contract, did those products come to you directly from the pharmaceutical companies or were they held by the Regional Transfusion Centre?

A. I honestly cannot remember because the blood bank, our blood bank, made -- I think they were delivered directly, you know. I don't think they went through the Blood Transfusion Service, but I can't remember. The NHS BPL, obviously, came via Transfusion Service but I really can't remember. My main concern was is there enough in the fridge, you know.

Q. In terms of then NHS product, any cryoprecipitate that you used came presumably from the Regional Transfusion Centre?

A. Yes, it did.

Q. You didn't have any difficulties with supplies for that. There was always sufficient?

A. Never, never.

Q. We have talked a little bit about the NHS Factor VIII and that you never had any difficulties with supply. Again, can you recall how orders for that were made? Did you make those directly to the Regional Transfusion Centre or did that go through Dr Swinburne?

A. No, it didn't go through Dr Swinburne, it was direct. It would be through the blood bank. I mean, it's interesting that the blood bank you're talking of -- blood bank were not really trained to deal with pharmaceutical products and yet they were dealing with them on the other end. The BPL material was a pharmaceutical product which was going through the Blood Transfusion Service, which they were not trained to deal with pharmaceutical products, you know.

Q. So I'm now going to move on to a different topic and that's knowledge of risk. I ask you to cast your mind way back and tell us what you can recall from your medical training, so both, you know, while you were at medical school but also you described training at the Blood Transfusion Service, and so on, in the 1970s, what you were told what you understood about the transmission of viruses through blood and blood products.

A. Undergraduate days we would have known very little

about it but once we started the post graduate and including doing MRCP, you did know that blood products' blood transmitted viruses -- not just viruses, blood-borne pathogens. We knew that from the day blood transfusion started. Certainly you wouldn't have passed the MRCPath without knowing about blood-borne infections. I know in your knowledge you mentioned viruses from 1946 or 1940s. In the 1920s there was transmission of measles from blood transfusion, and we know about malaria. We know about other protozoans. It's only logical that anything that's in the human body, if you take a tissue from there and give it to anybody else, whatever that tissue has there's a potential of transmission and that applies now, as well.

So in terms of post graduate, we would have known about transmission about blood, you know from, blood products and blood transfusion, because you were giving transfusions. I mean, we were all training as either physicians or haematologists or pathologists or whatever. We were responsible for giving not just blood, blood products, plasma, cryoprecipitate, et cetera. You shouldn't have been doing that unless you knew that there were dangers to giving these materials.

Q. What did you know about hepatitis B?

A. Well, hepatitis B was the well-known one, you know. The knowledge about hepatitis B -- because there was also a question of vaccinations, and so on. So, yes, that -- but blood was being screened, et cetera, so that was well-established, and then obviously then we knew about hepatitis A. What we didn't know enough was about hepatitis C and other viruses, it wasn't just hepatitis C.

Q. So do you recall during your training, your post-graduate training, learning anything about non-A, non-B, as it was then?

A. I'm sure it was mentioned but I think one of the problems was we did not know how much importance to place on it or the interpretation. I mean, transaminitis is a strange terminology, isn't it, how can you have inflammation of viruses -- of enzymes? Transaminases are viruses and you say transaminitis is inflammation of viruses; that's crazy. That's because -- that term was used because of lack of knowledge of what it meant.

Q. When you arrived, when you were a House Officer, a Senior House Officer, Registrar and then a Consultant, what journals or periodicals would you have been reading on a regular basis to keep yourself

up-to-date?

A. Well, the top journals -- I mean, New England Journal of Medicine, superb, which I subscribe to, British Journal of Haematology, which was our haematological journal. I was a member of BMA so I had BMJ, again pretty good. The Lancet I didn't subscribe to, but it was obviously very good, top scientific -- I had a few others as well, which I can't remember, but these are the top journals. Journals are very, very important because they were peer-reviewed, very reliable, especially if you looked at who the authors were. But I think something you have got to be aware of, that by the time things were printed in journals, there was already a delay, maybe six months, maybe a year, by the time they got peer-reviewed, corrected, et cetera. Very good information but often a bit late.

Q. So you have already said that you were desperate for knowledge, other sources of knowledge appear to have been the UKHCDO, meetings with other colleagues like Dr Swinburne in the regional meetings, information from pharmaceutical companies about their products. Are there any other sources of information that you were using at that stage?

A. Do you know, it's partly amusing, actually, that often, even now, information that comes out in the

Financial Times is probably quicker than it does in medical journals because of variation in share prices, et cetera. So, I mean, yes, the media was often quite important because they picked up information either in reality or gossip. But, yes, I mean, it could have been any source. It had to be verified. Haemophilia Society was also a source of information.

Q. We will come on to some of the publications in due course.

Did you watch the World in Action documentary Blood Money in 1975?

A. I must have watched it, I think I must have.

Q. Do you recall it creating any kind of impression on you?

A. They all made -- all these programmes had a great impression on me because I think they showed the human face of medicine. They are dealing with people, patients, not just concentrates and viruses, you know. I think this is the sad bit about haemophilia care: you were -- it had a human face, there was actual suffering, terrible suffering. And it wasn't just about what we -- mostly discuss about, you know.

Q. So if we take 1978 as the time that you go to Leeds and Bradford, presumably you knew by then that hepatitis B was a potentially serious condition that

could have long-term consequences and was transmissible by blood and blood products; is that knowledge you had by 1978?

A. Oh, absolutely. Yes, I did, yes. I think, '78 -- so that was -- that was four years after graduation. Yes, I would be doing the MRCP. I think it's something you had to know.

Q. You've mentioned in your witness statement that you had knowledge and that single donation products such as fresh frozen plasma or cryoprecipitate were safer than pooled products?

A. That's very logical actually, isn't it?

Q. That's knowledge you would have had by, say, 1978?

A. Well, we knew, and I think most clinicians would have known, that if a single unit of blood or single unit of plasma or cryoprecipitate has potential of one in whatever of passing on infection, British donor -- much lower than American and so on -- that we would then give six units of cryo, which is roughly what we used to give as standard for knee bleeds and so on, then it's six times.

Then if you go into a thousand, 500 or a thousand, it's that -- as many times. And then if you go to commercial products, and say 20,000, 30,000, it's just logical that whatever's wrong in there is

going to be transmitted, you know.

Q. Now the Inquiry sent you a number of articles that were published in the 1970s on non-A, non-B, and I'm just going to take you to a few of those.

Henry, could we have NHBT0000092_002.

This is a publication from Vox Sang from 1977.

I'm just going to go over to page 2, please, right-hand column, last paragraph:

"Although non-A, non-B hepatitis is, on the average, less acutely severe than type B hepatitis, it can cause severe acute disease and, more disturbing, it appears to have considerable propensity to progress to chronic hepatitis. The major thrust of post-transfusion hepatitis research must now be directed at developing detection methods for the non-A, non-B agent(s) or developing some reliable method of viral inactivation or removal which would be independent of testing."

Do you recall -- would you have seen this article, do you think?

A. I can't -- I can't recall this at all. It's before I was even appointed, actually. And it's not in a sort of a journal one would be reading as a registrar. It's specialist. But what it says is true, isn't it?

Q. Yes. And do you recall whether or not that kind of information is information that you knew by, say, 1978?

A. I can't recall it but I do not think -- I don't think it would have been in the mainstay in my brain, you know, about this, because I wasn't actually practising proper -- you know, haematology to do with blood products, really. But what it says, it makes sense, you know.

Q. So, then the next article is RLIT0000228.

Again, this is a 1977 publication. So at this point you are a senior house officer in pathology in Manchester. Again, is this something that you recall reading at the time?

A. Not at all.

Q. Just look at the summary there.

SIR BRIAN LANGSTAFF: If he doesn't remember it, shall we move on to something else.

MS SCOTT: Then the next one is PRSE0003622.

Q. This is September 1978, so by now you're between Leeds and Bradford. I understand you started your senior registrar in haematology in August, so this is coming out just after then. You said you didn't get The Lancet, but do you think that's something that you could have come across, given that it was in

The Lancet?

A. I think this publication is a major publication.

Q. Yes.

A. You know, it's a very, very important publication, by very important people. I've seen this a few times, maybe not in '78 but certainly in the last 20 years.

Q. Can you recall when you did see it first?

A. This would have been discussed in the first meetings that I went to, in international or national. There would have been presentations by Eric Preston or one of the others, maybe Dr Triger. You know, it's possible. So I would have come across it from 19 -- in the early 80s, really.

Q. So you think that's something you would have come across in meetings, as a Director of the Centre, UKHCDO or other international meetings, in the early 80s?

A. This material would have been quoted or mentioned. All right, it's a few years later, but it's a very, very important publication, this.

Q. And you don't think it's something that would have been talked about on the wards with Professor Turner, for example, or Dr Swinburne, when you were working between Leeds and Bradford in '78?

A. No.

Q. Because those sorts of discussions just didn't take place?
A. No, because we had our own clinical practices and we never had -- or hardly ever, I think, we had joint meetings to discuss scientific papers or scientific knowledge or even -- even management of haemophiliacs as such. They were rare and in between. Maybe there should have been more meetings, more regional meetings. I think we had attempted to try to have more regional teachings but they were rare events, if they were at all, you know.
Q. Just looking at the summary in this paper:

"Systematic screening of 47 haemophiliacs in Sheffield revealed abnormal liver-function tests in 36 (77 per cent) with a tendency for these abnormalities to persist. To assess the importance of these abnormalities ... liver biopsy was carried out on eight symptom-free patients ... A wide spectrum of chronic liver disease was demonstrated, including chronic ... hepatitis and cirrhosis."

So would you accept that by the time you did become aware of this paper, for example, in -- I think you described in the early 80s, that you were aware that non-A, non-B was a clinically significant condition that carried a significant risk of causing

liver disease?
A. My first unfortunate experience with hepatitis, non-A, non-B, was at St James's when I was Senior Registrar. A gentleman came in, in his 70s, for a prostate operation. He was a mild haemophilic. He had never, ever been exposed to concentrates or cryo or any other blood products related to his haemophilia. I think his level was about 34 per cent or so, and he was treated with Factor VIII concentrate. I don't know whether it was commercial or whether it was NHS. He became jaundiced within about three or four weeks and he died.

Now, that's the sort of education you don't forget, that people who have never been exposed, that were given concentrates could give them non-A, non-B hepatitis and it was not a benign disease.

My other experience, which again, and I feel very sad about it because he was a very, very good friend, haemophiliac in Bradford in the early '80s. He had liver disease with a big enlarged spleen, quite advanced liver disease, and he -- my predecessor should have advised him not to have alcohol, you know, which he did and I used to advise him not to drink alcohol. Now, alcohol and non-A, non-B hepatitis, or hepatitis of any sort, they don't go well together at

all. So one of the things we always did was to advise -- and he died because of his non-A, non-B hepatitis. So, yes, the lessons were there. I didn't need a biopsy to tell me that some of these people died from non-A, non-B hepatitis, that it wasn't a purely benign disease.
Q. That first experience that you had at St James's, that would have been somewhere between 1978 and 1981?
A. Absolutely, yes.
Q. Given your previous evidence, I suspect the answer to this is no, but was there any discussion, any opportunity during that period, for you to discuss liver disease, for example, with your colleagues who were working in the liver units and liver specialists?
A. Yes, because if -- now, again, I can't tell you the exact times but I was in quite close links and talks, and Dr Bacarius(?) from Sheffield used to come to Bradford and give talks. I used to get people to come to Bradford, even like Tuddenham and Rizza came -- he was one I could listen to and I used to, but we had our own liver specialist and we used to work closely.

If there was any inkling that there was significant liver disease then I would involve the hepatologists but we did not do liver biopsies.
Q. So, by the time you were centre director, you have

described how you had -- you know, you wanted to give people a good training and that seemed to make the hospital attractive to clinicians and students, and so on, then there was an opportunity for education from liver specialists, and so on. But before that, in the era where we're talking about, where you are working in 1978 to 1981 with Dr Swinburne and Professor Turner --
A. Yes, sorry, my previous answer was when I was already director.
Q. Yes.
A. Now, '78 to '81 I don't think liver disease was discussed at any time -- mentioned maybe, yes. When I was senior registrar in Jimmy's, Dr Swinburne was immunologist. She never actually -- we never had any formal training from her about haemophilia, et cetera, although she was the director. We used to work with the haematologist Dr Barnard, and so on. But the focus was on malignant haematology and at Bradford, as you know, we had Professor Turner who was not well and never got involved in -- so our education as Senior Registrar was quite inadequate, you know. I think this applied to a lot of parts of Britain, by the way. We were not unique.
Q. So as this knowledge about non-A, non-B was emerging,

would you agree that patients being treated with factor concentrates should have been told about the risk arising from their treatment with factor concentrates?

A. Patients were quite aware about viral infections because, you know, even -- they had their own groups, support groups, and certainly when I was consultant we had set up a group through the nurses, and so on. They were quite well informed by the society and so on.

We always told them -- well, we always had a programme for vaccinations so they knew why they were getting vaccinations.

Q. For hepatitis B, would this have been?

A. Hepatitis B, yes. So it wasn't as if they were completely ignorant of the fact that -- what we were trying to do.

What was difficult -- there were two areas of difficulty in the early 80s. One was if you had abnormal liver function enzymes, you know, what we call transaminitis, what it actually meant. So the best thing we could do there was do tests and tell the patients that, "You've got slight elevation of your liver enzymes and we're keeping an eye on it."

Now, raised transaminases are very common even

now, you know. In my case, my transaminases were elevated. The doctors thought I had haemochromatosis and I didn't. It turned out it was a fatty liver. Very common to be raised transaminases in diabetics, et cetera. So it wasn't just confined to haemophiliacs. So the interpretation was difficult, and we couldn't, obviously, do liver biopsies. You could do ultrasound and so on, but they were told that "We are watching". Every three months, we used to keep an eye on it and if they went beyond a certain level, then I would refer them to a hepatologist.

Q. Were they ever told they had or that you thought that they had non-A, non-B hepatitis?

A. You've got to be careful because you are saying "non-A, non-B" and "hepatitis", so when you use the word "hepatitis", that brings a picture of inflamed liver, "Oh, I'm sick, I'm ill", okay?

"Non-A, non-B" implies there's a C to Z, you know, which we didn't know anything about. So the patients were told that they've got possibly a slight inflammation of their liver, which in medical terms is hepatitis -- we might not have used that term -- and that we're watching their enzymes and they must not drink alcohol. I think that was something that would have to be told to them universally you know. That's

very important.

Q. Would they have been given advice about infecting -- potentially infecting other people --

A. If we knew that it was non-A, non-B hepatitis, then obviously we would tell them. If they had hepatitis they would be told. But, like I said, the interpretation at that time was difficult.

Q. So --

A. That's why this liver biopsy, you know -- this was very important, you know, because what it said was: you can't actually rely on those enzymes only. So you can have very low enzymes and you can have quite serious liver disease and you can have very high enzymes, in which case you had hepatitis, non-A, non-B hepatitis.

The way the UKHCDO in the studies define hepatitis is 2.5 times the transaminases, you know, when you were dealing with products that were given. Well, if they didn't have enzymes that were 2.5 times, how could you then say, you know, you didn't know? I mean, did I have hepatitis when I had raised enzymes? No, I didn't.

Q. So in the late 70s, early 80s, how would you diagnose non-A, non-B in one of your patients with --

A. Well, you had to look at the enzymes but also you were

looking at -- like I mentioned about this patient where he had a big spleen -- enlarged spleen at the same time, or if there were things that related to liver disease, other signs and symptoms of blood tests, you know, that -- then, yes, they would be investigated but simple raised enzymes by itself was very difficult interpretation for us.

Q. So patients that were coming in with raised enzyme levels, from your evidence, very unlikely you would have mentioned non-A, non-B hepatitis to them?

A. I think it's very unlikely we would have said they've got hepatitis, but we would have said that, "You have got slight inflammation", which is the same thing, "There is a possibility you've got inflammation of your liver, and it's not hepatitis -- we don't know, you know, it's something we have to keep an eye on, but avoid alcohol intake."

Q. But unlikely those patients would have been given advice about not infecting others because the diagnosis --

A. Well, if you proved it was infection, then yes, we would tell them --

Q. But just with the raised transaminase you are saying that you wouldn't have known it was an infection?

A. No, we wouldn't have.

And like I said, maybe 10 per cent of all UK residents have raised transaminases.

Q. Did you have any patients that had the raised transaminase plus, if I can put it that way, so other features that would lead you, over that period, to diagnose them as having non-A, non-B?

A. Yes, there would be, and that's where I would seek professional help.

Q. And you recall having patients?

A. You know, from liver specialists. Sorry?

Q. You recall having patients?

A. Well, I just mentioned one that died. But one of the impression was that it was a benign thing, as you know, and this -- the thing about the study you've shown is that it's not that benign. You know, now we know that it's not that benign. Because people like Eric Preston were brave enough to do liver biopsies.

Q. So for those patients where you thought, well, actually, there may be non-A, non-B here, you've described that you would seek help from liver specialists?

A. Yes, if there was a reason to worry, if they were increasing, if they were unwell, then we would seek -- I would probably have done an ultrasound, you know, in the first instance as well.

Q. What would you have told the patients?

A. They would be investigated.

Q. Would you have told them about hepatitis?

A. Yes. But like I said, they were also very well informed, you know. But yes, we would have discussed it, yes, the possibilities, et cetera. I think it depends on individual circumstances, isn't it? I mean, you're asking a generalisation, and patients, you can't -- they are individuals at the end of the day.

Q. But if you suspected non-A, non-B, would you give -- irrespective of who the patient is, would you have given advice about not infecting others, do you think?

A. If the suspicion was high enough, if there was sufficient abnormality, then the answer is yes. But, you know, one of the problems is, like I said, you think non-A, non-B, how much knowledge did we have, otherwise we wouldn't call them non-A, non-B until we had the hepatitis C diagnostic test. You know, it was a grey area for everyone.

Q. So were you cautious about passing this information on to patients during this period before hepatitis C had been described?

A. One thing about haemophiliacs, most of them were intelligent. They were very nice people, very

intelligent, they had come to know me and my staff very well and we could talk, we could discuss things. There was no problem discussing anything about their tests at all, at any time.

I think the danger was when you didn't discuss or you kept things away from them. Honesty paid with patients, haemophilia patients, because that was something they had to latch on. There wasn't much they could -- you know, we were their friends. They had to rely on what we said. Doctors were terribly important to them, you know.

Q. I'm going to move on now to knowledge of HIV. Can you recall when you first became aware of AIDS?

A. Like I said, we were always desperate for knowledge and information and, as soon as -- it must have been -- the first case, I think, was in '83, wasn't it, I think. I think by '84, '84 we were aware. As soon as the tests came, we tested people. So it must have been around '84, I think. I can't recall when the tests were. Was it 1984 it was available?

Q. I will show you some documentation in relation to that in due course.

So can I ask you again, the Inquiry have sent you a number of publications that were coming out at around the time the information about AIDS was

emerging. First one is PRSE0000523. This is the MMWR report from July 1982 and the first paragraph there says that:

"CDC recently received reports of three cases of [PCP] pneumonia among patients with haemophilia A and without other underlying disease. Two have died; one remains critically ill. All three were heterosexual males [with no IV] drug abuse."

And all had lymphoma, et cetera.

SIR BRIAN LANGSTAFF: Lymphopenia.

MS SCOTT: Sorry. Then over the page, page 2 under "Editorial Note", second paragraph down:

"The clinical and immunologic features these three patients share are strikingly similar to those recently observed among certain individuals from the following groups: homosexual males, heterosexuals [IV drugs abusers], and Haitians who recently entered the United States."

Then:

"Although the cause of the severe immune dysfunction is unknown, the occurrence among the three haemophiliac cases suggests the possible transmission of an agent through blood products."

Then the last paragraph on that page, it just notes:

"CDC has notified directors of haemophilia centres about these cases and, with the National Haemophilia Foundation, has initiated collaborative surveillance."

Would you have seen that; is that something you would have seen at the time?

A. Yes, I was aware of that, yes. I can't tell you exactly which date or when. That may have come from one of the documents I gave you, I don't know.

Q. So it came out in July 1982. Do you think you would have seen it fairly soon after that?

A. I might not have seen it because it's American but I would have heard of it. I mean, that was big news, wasn't it? Very relevant.

Q. Yes, and you're a centre director by now --

A. Yes.

Q. -- and having discussions with your colleagues at presumably quite a high level and that's something -- so reasonably soon after this came out, you think it's likely you would have been aware of it?

Then, Henry, if you can go to PRSE0002410, which is a paper from the New England Journal of Medicine from January 1983. I think you said you had a subscription to this journal; is that right?

A. Yes, I had the New England Journal, yes.

Q. If we go, Henry, to the right-hand column, last paragraph:

"Now we are becoming aware that treating haemophiliacs with Factor VIII preparations may exact a high cost. Reports from the CDC include three haemophiliacs among cases of Acquired Immunodeficiency Syndrome. Only recently recognised, this syndrome is associated with abnormalities of immuno-regulation and a profound susceptibility to opportunistic infections; it is eventually fatal in many patients."

Then over the page, please, Henry, to the -- again, last paragraph on that left-hand column:

"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."

Do you recall having discussions then with your colleagues about the recommendations in here or the suggestions in here?

A. I can't recall having discussions within the region, you know. I'm not even sure whether there were communications. There must have been something but this was at a time we were listening very carefully to UKHCDO, and there were a lot of mixed messages, you know, starting from "Oh, it doesn't apply to British

products", that this is a one-off, this is early, et cetera. What were we to do about it? It's just too early. I don't think we could have done anything really. We were waiting, again, for instruction or guidance or ...

Q. We will look in a moment about some of the messages that were coming from UKHCDO. I want to take this in chronological order, if I may.

Henry, can we have PARA0000013. Now, this is a document that was in your papers and it seems to be a meeting from 8 March 1983. It's not a terribly good copy but it seems to be the Haemostats Club?

A. Haemostasis Club.

Q. What was that?

A. I don't know because it says Professor Jeanne Luscher. That's American. So whether this was from there or whether somebody had copied -- you know, typed out information from that Haemostasis Club, I don't know but it says Professor Jeanne Luscher, and it starts very strangely:

"Or if you have missed Herpes this is all you need to know ..."

Q. Yes. So if we turn over the page to three paragraphs up:

"There are no reports of AIDS in UK

haemophiliacs yet."

It does seem to suggest that this is a paper that was concerned anyway with the UK, albeit given by an American professor?

A. But I think there was a Haemostasis Club in UK. So whether they transcribed, you know --

Q. Do you know --

A. I wasn't part of it.

Q. You weren't part of it. Did you ever go to any of their meetings?

A. No.

Q. Do you know who was a part of it?

A. Well, it would be some members of the UKHCDO and -- I honestly couldn't tell you but it wasn't --

Q. So this is not a meeting you would have gone to?

A. No, or whether it was something in the south-east, you know, around that area. I don't know.

Q. Do you have any recollection of how this document came to be in your possession?

A. No, I can't recall whether -- it's been sent to me obviously. Whether it was sent through the region, you know, through Leeds or whether it was sent from somewhere else, I have no recollection. It's a very poor type, isn't it?

Q. It is. And unfortunately some of the bottom half of

the second page is missing as well.

So can you help us at all with when you would have received that?

A. No, not really. But it's an important document, and I think it's from the UK haemostasis group. And I think it would be -- it would have involved the directors from south-east England, you know.

Q. Did you have a channel of communication with them for the exchange of information?

A. No, not really. No.

Q. We can see what is being said there, that the distribution of those with AIDS: 1 per cent haemophiliacs. That's under "Distribution", and then --

SIR BRIAN LANGSTAFF: I think you are on the previous page, are you?

MS SCOTT: Yes, sorry.

First page, sorry, Henry.

So under "Distribution" we can see:

"Haemophiliacs: 1 per cent."

And then under "Geographical Distribution", it says:

"Mortality: 80 per cent so far."

SIR BRIAN LANGSTAFF: Just pausing there, that 1 per cent is 1 per cent -- let's just go the page a bit please,

Henry -- of the 1,250 cases.

MS SCOTT: Yes.

SIR BRIAN LANGSTAFF: So that's going to be 12 cases.

MS SCOTT: Yes.

Then underneath "Mortality" it says:

"Communicable disease centre [CDC] in USA postulates that AIDS is caused by transmissible agent (probably new or variant [sic]" --

SIR BRIAN LANGSTAFF: "Mutant".

MS SCOTT: "Mutant", sorry.

"... mutant virus) which entered populations in 1978/1979 ..."

Then it says:

"Problem accentuated by 'fast lane' type individuals with as many as 100s - 1000s of sexual contacts. These individuals also tend to sell or donate blood - hence the possible reason for haemophiliacs coming into the chain."

Then over the page:

"AIDS shares some common properties with Hepatitis B, i.e. long incubation period which has been deduced from victims who have received only one blood donation contracting AIDS 12 months later."

Then below "Immunological Defects" it says:

"It is possible that haemophiliacs have altered

T4/T8 ratio and immune status from continual antigenic bombardment, and therefore succumb to AIDS type virus more easily."

Then it sets out the recommendations from the US National Treatment Council:

"1. Use cryo or [fresh frozen plasma] for children under 4 ...

"2. Use DDAVP where possible.

"3. Do not undertake elective surgery if possible.

"4. No longer obtain concentrate donations from high risk areas.

"5. Attempt to screen out high risk groups eg use questionnaire ...

"6. Heat treat concentrate to reduce virus ...

"7. Suggestion raised to use Porcine Factor VIII, only [question mark] what grotty viruses do pigs have?"

And then it says:

"There are no reports of AIDS in UK haemophiliacs yet."

Then there is a paragraph at the bottom of that which is cut off:

"There was some discussion relating to lack of cases in UK but it was pointed ... [something] the

epidemic may yet come.

"The implications of this happening are cause for great concern."

So would you agree that that --

SIR BRIAN LANGSTAFF: We have missed that. Is that on the other page?

MS SCOTT: Sorry, the next page. Go over to the next page:

"The implication of this happening are cause for great concern."

So would you agree that that document contains really all of the key information about AIDS: that it's via a transmissible agent, blood; haemophiliacs are at particular risk for that reason and so on; and setting out treatment recommendations. So that document provides all the key information that would be of huge significance to somebody treating people with haemophilia in March '83?

A. Absolutely. And I think all that information is American. Obviously, somebody's brought it to the haemostasis club here, I think, in the UK, and printed it very badly. And it's also -- the last paragraph is slightly mixed up with -- that's acute lymphoblastic leukaemia trials but anyway.

SIR BRIAN LANGSTAFF: Can you help just on the point of

whether it's American or British.

Dr Lilleyman; do you know of Dr Lilleyman?

A. Yes, he's a paediatrician.

SIR BRIAN LANGSTAFF: In England?

A. In England, yes, it's British. But Luscher is American.

SIR BRIAN LANGSTAFF: Yes. So it seem to be a rather mixed production.

A. Yes. But I think this was always important, that what information -- Americans were well ahead with information, research, et cetera. It's how we translate it to Britain. And if it was now, it -- I presume there are organisations in Britain that would have picked up immediately and taken action, you know, to -- that since whatever -- whatever, you know.

Here it seems that you had the information, it was how it was going to be used in Britain and who's going to be responsible for noting this information and doing something about it. And people like us were really waiting for instruction, basically. Not just knowledge, but instruction.

And if there was any suspicion of any of the products having this -- because it says that the American product, they were already thinking of litigations, they were already putting warnings on the

products, but the same products were coming here and nothing was happening. And we were not independent to make decisions of ourselves. We needed guidance. We needed leadership in this.

Now whether that leadership could have been from UKHCDO, it could have been from Medicine Agency, it could have been from all sorts of things, but it didn't -- I don't think we actually got -- but there was a lot of this business, "Oh, we're not sure what it means", "Oh, British products", "There's been no cases in Britain". Well, once you get cases in Britain it's too late, because the horse has bolted, and that's exactly the history. I think that's what happened is we got all these cases after -- while people were waiting for them to happen, and they did happen.

SIR BRIAN LANGSTAFF: And about this time there was quite a lot of talk in the press I think, in New Scientist and The Observer, in January of 1983.

A. Yes.

SIR BRIAN LANGSTAFF: So that obviously is the press. And you may read the media, I suppose, with the same eye that others do, you may think, well, do they really know what they are talking about, and you -- but it does raise questions, doesn't it?

A. Yes. And this is where I must say I feel sorry, you know, that with better guidance, better leadership, from whatever source -- you know, we were only minions in the big cog. We were not even a Reference Centre. But with better leadership from whatever source we may have saved some cases. Not all. We may have done better than we did.

SIR BRIAN LANGSTAFF: You said that this particular document, in March of 1983, was a particularly important document to you?

A. Yes, but I can't recall when I received it or how I received it. But it's a very important document, and I'm sure you will be able to find out what this "Haemostasis Club" is and find their minutes, you know.

SIR BRIAN LANGSTAFF: Why do you regard it as so important, this particular document?

A. Because it looks like pre-publication. It looks like -- you see, one of the things that -- there were small groups in America that produced their own newsletters. I'm trying to think of the lady that used to do it in California. She used to produce her own newsletter. And I think this Luscher may have -- this information may have been from within their own discussions. But as I mentioned before, by the time

it reached publication there would be a delay of a year, maybe six months. So I suspect this was probably being discussed because there was -- possibly to help litigations. You know, they are already talking of somebody being sued.

I think Americans are well aware of possibilities -- what -- if things went wrong, therapeutically. You know, unlike in Britain. Now it's obviously different, you know. I don't know.

SIR BRIAN LANGSTAFF: Thank you very much.

MS SCOTT: So having seen that New England Journal article in January 1983 that we went to earlier, would you agree that patients around about that time needed to be told that there was a real risk that blood products could transmit AIDS, not that it was certain but that there was a real risk that that was the case?

A. You know, if you did that, what were the alternatives we were going to offer them? You know, it's like when you do a blood test, if you get an abnormal result -- if you are going to do, then you should know what you're going to do about it.

I think at that stage what we were really saying to everybody, and to ourselves, or convincing ourselves: let's wait for more information from people who are more learned than me. You know, who have more

at risk than me, more patients than me. Let's try and hear from the people who really matter in this country.

And we were getting very mixed messages, as you know. And I think you've got all those articles and documents to see what mixed messages they were.

Q. So there was no solution that could come from the medical world at that point but it would have made a difference to patients, wouldn't it, because they would have then had a choice about whether or not, for example, they wanted to continue with their treatment or what decisions they were going to make about their treatment, knowing the risk?

A. You see, the alternative, if we were talking to them then they would say: well, Doctor what about NHS factor? You couldn't say NHS Factor VIII from up to 5 to 10,000 donors couldn't carry a risk. You couldn't say that.

Q. No.

A. If you said, okay, go to cryoprecipitate, you couldn't promise them and then tell them to use cryoprecipitate which is really a very, very difficult thing to use, you know. So what you would be telling is: okay you're going to go backwards to the treatment of the '60s and '70s, you know. You must -- at the end of

the day, Factor VIII revolutionised haemophilia care, you know, from -- I mean, if you had seen how badly deformed -- what deformities haemophiliacs had and what sort of lives -- and the lifespan was reduced down to 40 or 50 years in the 1950s, in the '80s their lifespan was normal.

So I think one has to be careful to say, look, we're going to turn the clock back, now, sorry we made a mistake or we think we are going to make a mistake; it doesn't quite work like that. What we needed was to say: right, this is a possibility, what is the Government doing, what is the Health Services doing, what is the Reference Centres doing, what are the scientists doing, what are the pharmaceutical companies doing about this?

I think they were trying, I think they were trying to very hard. But I think in America they were trying harder than we were trying in Britain, although America had obviously their own problems about their donors, and so on. Britain was an ideal place, actually, because there were good British donors well tried out, and maybe the BPL and NHS should have taken a lead there, you know.

Q. When do you think that you did start telling your patients about the risk of AIDS?

A. I think when we knew the risks of AIDS or what are the chances of risks of AIDS. You see, by the time we could test people for AIDS they were already positive. There's quite a lot of them positive. I think in our centre probably less than other places, and I think what you've got with Adrian Minford, there were four kids, children, which is low but serious. But by the time we were able to test them, quite a lot were already infected.

Q. So do you think -- and I appreciate I'm asking you to remember things a long time ago -- but do you think you weren't having discussions with your patients about the risk of AIDS before the test became available, for example?

A. We might. I cannot tell you because they read the press, you know. They have access to media, as much as I have.

Q. So patients were coming to you in clinic and asking about it, were they?

A. They probably would have and I would have talked frankly about it.

Q. Do you have any actual recollection of that?

A. I couldn't because it's a whole period full of -- there were memories we didn't really want to bring back until this, you know. We had ourselves, as

directors, had quite traumatic period, you know, in the '80s.

But I can't recall, honestly. I could try very hard but we were -- you see, at that time in the '80s, there was a lot of resistance from the gay rights group that we shouldn't even be testing people, you know, that it was -- we shouldn't be testing them and we shouldn't be telling them and in Bradford I remember having a difficult time because, all right, you should counsel them and test them, and so on, but there was this opposition that you should keep HIV out of, well, hospitals, everywhere, you know.

Sorry, I'm ...

Q. No, don't apologise to me. During the time you think when you started speaking to patients about AIDS was when you knew -- you said when you knew about it, when you understood that it was transmitted by blood; is that when you think you would have told them?

A. I think the main time to discuss and talk about this was when the test was available because it was very important that we share it --

Q. That was something you could do?

A. Yes, but there was a moment that said don't tell them, which I totally disagreed with them. Actually, when you look at the earlier -- you showed some

comprehensive care, you'll see that we tried to have a counsellor, social worker, et cetera, you know, we tried to have a comprehensive -- and we tried to have clinics where we could give them time to talk about it, you know. So as soon as there was any possibility of patients having HIV, we would discuss it, you know.

Like I said, you can achieve a lot of things by being honest with patients. They are quite intelligent, very knowledgeable, generally.

MS SCOTT: I note the time, sir, we are going to look at some of the contemporaneous documents after lunch and it may be that that will assist your memory.

SIR BRIAN LANGSTAFF: Yes, we will take a break now until 2 o'clock. So 2.00 the same rules apply. So 2.00, please.

(1.01 pm)

(Luncheon Adjournment)

(2.00 pm)

MS SCOTT: I'm going to ask you some questions now about some documents you have mentioned both in your witness statement and this morning and it's the statement -- you mention that you were getting conflicting information about AIDS, in particular from UKHCDO, and you exhibit to your witness statement a letter written by The Haemophilia Society which quotes

Professor Bloom in May 1983, saying that the cause of AIDS was quite unknown and it has not been proven to result from transmission of a specific infective agent in blood products. You are familiar with that letter?

A. Yes.

Q. Professor Bloom also makes a similar-ish comment in October 1983 at a UKHCDO meeting that you attended. He said:

"There's no need for patients to stop using commercial concentrate because at present there's no proof that the commercial concentrates were the cause of AIDS."

The Inquiry has looked at both of those documents, particularly that latter document, a minute of that latter meeting on various occasions. Can you recall that meeting? Do you remember that meeting in October 1983 when Professor Bloom made that comment?

A. Not the meeting itself. I don't recall the meeting itself but I would have been there. I think I was there.

Q. But you do recall seeing the letter from The Haemophilia Society in May 1983?

A. Yes, yes. That was in my possession, so ...

Q. Indeed. That was in your possession, exhibited to your witness statement.

Can you remember now what you thought about that, about what Professor Bloom was saying, given that you had, for example, read the January 1983 Lancet article which said something rather different? Do you recall being surprised at what he was saying at that stage?

A. Confused.

Q. Sorry?

A. Confused.

Q. Confused.

A. Because -- and it's odd, actually, you know. I think to make a blatant statement like that it's a bit unusual, you know, to -- a lot of medicine, if you've got evidence somewhere else of something like this, then you've also got to think of probability. So you can't make -- with human beings when you're dealing with them, you can't say: right we're going to -- we must have at least ten people in this country who are infected and three dead before we make a statement. A statement should have been based on probability and saying: it's likely but there's no evidence yet. So I was a bit surprised and it's confusing.

I know why he was doing it, he was trying to reassure the haemophilia population that don't rush off to your centres and demand change.

Q. So at the time, as you say, you were confused, was that because you knew that what he was saying was inaccurate and it was confusing why would he be saying this?

A. Yes, why would he be saying that? Not inaccurate, I wouldn't say it's inaccurate; it's probably accurate.

Q. Yes.

A. But, you know, to tell a lot of people something that could potentially be proved wrong it's not what I would call a good politician, you know. That's a wrong ... but that's not the sort of thing a person in public eyes should be doing, you know.

Q. Presumably, your patients were reading this letter --

A. Yes.

Q. -- and not many of them, if any of them, would have had access to the sort of Lancet articles and other material that you and other clinicians have been able to read. Did that concern you, that the information that they were getting from The Haemophilia Society was giving this particular impression which, while accurate, may have been misleading?

A. Well, he wasn't wrong but it's not the sort of statement you'd make. So, in a sense, I think he was trying to reassure the haemophilia population and it

obviously made our job that bit easier, because we didn't have loads of people ringing up, you know, about it. But it's an unfortunate -- I think it's an unfortunate letter. It's an unfortunate statement, specially from somebody like Professor Bloom who is very highly regarded. But how much pressure he was under to make a statement like that from the society, I don't know.

Q. Did it concern you that that was the information that your clients were getting?

A. Sorry?

Q. Did it concern you that that was the information your patients were getting?

A. I can't remember what I thought at the time.

Q. Do you recall whether or not, for example, you would have done anything in discussions with patients to actually make a rather more balanced appraisal of the risk?

A. This is a chronic cough, by the way.

Sorry, could you repeat that, please?

Q. Yes. So do you recall whether you would have raised this with patients and given them perhaps a more balanced appraisal of the risk?

A. I wouldn't have raised it with the patients but the patients could have raised it with me, if they wished.

Q. In response, would you have repeated what Dr Bloom says? Can you recall any --

A. No, I wouldn't have repeated it because we were all aware that some things were happening in America that ultimately would come here because it's the same product, you know. So I think I would have probably said let's wait and watch and see what happens and, as developments happen, as new information comes I will keep them informed and take action. There are actions I've taken. I think you may come to that later.

Q. Yes.

Can I then move on to the other document I think you have referred to, which is the recommendations from UKHCDO if we can look at that, Henry, it's HCDO0000270_004. This is the 24 June 1983 Acquired Immune Deficiency Syndrome letter which you received from UKHCDO as a centre director and it sets out there following the meeting, this is the second paragraph down:

"At the above mentioned meeting on May 13th the following general recommendations were [made]."

Now, just before we get into that, is it your recollection that this was the first time the UKHCDO had made any sort of recommendation for treatment?

A. I don't know whether it's the first time but it's the

one that we followed. You know, it's good advice.

Q. So you have there:

"... mildly affected patients with haemophilia A or von Willebrand's disease and minor lesions, treatment with DDAVP should be considered."

So you say you followed that?

A. Oh, yes we did, yes.

Q. Was that a change of treatment policy?

A. No. I can't remember exactly when we started DDAVP but it was quite early because we actually did some studies as well. I can't tell you exactly when and what but we weren't strangers to DDAVP.

Q. So that was, in effect, really just confirming what you were already doing?

A. Well, I would think so, yes, absolutely.

Q. Then paragraph 2:

"... treatment of children and mildly affected patients or patients unexposed to imported concentrates many directors already reserve supplies of NHS concentrates ([whether cryo] or freeze-dried) and it would be circumspect to continue this policy."

We had a bit of a discussion about that this morning about what your treatment policy was at this stage and I think you were a bit unsure about what it was. Can you recall whether on receiving this

information, this letter, you changed your treatment policy?

A. I don't think we had to change. We were following it largely the same. I think Adrian Minford has put the same view, I think -- but you've got to remember that the way we treat patients it's -- there's -- you can have a guideline but it comes down to individual patients. So if a mildly affected patient was having a major operation, then DDAVP wouldn't work. It would be inappropriate. It wouldn't get enough. It would be an unreliable way of treating haemophilia because you couldn't predict what the response was going to be with DDAVP. Quite often, we gave a trial beforehand to see what sort of response they get, noted it so that we knew that when the time came we could give the DDAVP and we knew what the predicted response would be. But if it was a major operation you've got to have Factor VIII at surgical levels which is almost normal levels, otherwise there would be a danger of them bleeding.

So on an individual basis -- but generally we would follow this, yes.

Q. Just on that point for surgery, was it your practice to ever use cryoprecipitate as cover for surgery?

A. No. No, cryoprecipitate is very unreliable, very

cumbersome, takes a long time. Remember, when cryoprecipitate is prepared, if you don't give it fairly soon after preparation it itself has got a danger that it could get infected. No, cryoprecipitate really was not appropriate treatment.

Q. I think from your statement for the returns that we've seen, you were only using cryoprecipitate at this point for von Willebrand's patients?

A. Yes.

Q. Then, from your statement, it appears that you didn't use cryoprecipitate for people with haemophilia A, at any stage?

A. No, no, not generally and we used -- we had other bleeding disorders that we used cryoprecipitate. We were also a general hospital, so we had other bleeding problems that we used cryoprecipitate. So we did use cryoprecipitate in practice but, obviously, you know, this was as a general policy, yes, this is what we would have followed. On individual policy, it depended on the clinical condition that we were treating.

Q. So do you remember, after receiving this document, ever offering a patient cryoprecipitate?

A. I can't remember, no -- not with haemophilia, no.

Q. Not?

A. Not with haemophilia, no.

Q. Not with haemophilia, even though the risk would have been lower of transmission of virus?

A. Yes, but there were other risks with cryoprecipitate, you know, that really wouldn't have -- it wouldn't have made good medicine, medical practice. You know, cryoprecipitate it had a volume, it needed to be prepared, it was frozen, in a frozen state, there was delay in using it, unpredictable amounts of Factor VIII in it. There were a lot more impurities, protein impurities and other impurities, and you couldn't give vast amounts. There was a volume problem. So it's not the best product, really, to --

Q. Is it fair to say that, really, you didn't -- I think you've said in your evidence earlier Factor VIII was revolutionary it was the new drug, cryoprecipitate was considered to be old fashioned. Is it fair to say that, really, you didn't even consider going back to cryoprecipitate at this stage?

A. No, we didn't, no, unless it was for von Willebrand's, or Factor XIII we had deficiencies. There were other bleeding problems that we treated. We treated a lot more than other centres, you know.

Q. Just picking up on that point can we go, Henry, please to PARA0000015.

This is a letter we've looked at already this morning. It's the letter from Dr Swinburne to you on 7 July 1983 and we looked at it in relation to the contracting arrangements but it's the first paragraph I wanted to pick up with you now. It says there:

"I have discussed the supply of Factor VIII and related products with Dr Tovey. In the light of the discussions we had about AIDS he and Dr Rajah have agreed to look into the question of cryoprecipitate and to maintain the supply."

So I wonder whether you can recall the discussions that you were having with Dr Swinburne or the discussion you had with Dr Swinburne around this time about AIDS?

A. Yes, but you've got this letter and then at the same time you've got another letter that says that Dr Swinburne was in favour of commercial products, in the same letter that I'd said that I favour NHS concentrates.

Q. Yes, we're going to come on to that.

A. Yes. So these are sort of contradictions, aren't they?

Q. Yes, so do you recall the discussions that you had? The inference -- and I wonder if you would agree this is an appropriate inference to draw -- the inference

that could be drawn from this letter is that you've had a discussion about AIDS and a concern about transmission of AIDS through factor products has been discussed, and so you're looking into whether or not you ought to be treating with cryoprecipitate in order to reduce that risk?

A. Not necessarily because the question -- we use cryoprecipitate in lots of other things in haematology. So the fact that they were maintaining supply of cryoprecipitate was good news because we had DIC, you know disseminated intravascular coagulopathy --

SIR BRIAN LANGSTAFF: I'm not sure that's reading it right because "maintain the supply" may, and in context, perhaps does, refer to the opening words of that paragraph "I have discussed the supply of Factor VIII and related products". So quite what it means isn't entirely clear. It's only clear to those who were party to whatever was going on at the time.

Who is Dr Rajah?

A. Dr Rajah worked in the blood transfusion but his main involvement was because it was a cardiothoracic centre at Seacroft and his main concern was to do with cardiac surgery. He played almost no role in treating inherited bleeding disorders.

SIR BRIAN LANGSTAFF: So, in short, this is nothing to do with them looking into the question of what treatment to use, it's just a question of them both being involved in the supply side, looking to see whether they could supply perhaps more cryoprecipitate, perhaps the same amount of cryoprecipitate, it depends how you read it, and to maintain the supply of Factor VIII, if that's how you read it.

A. Well, I'm surprised Dr Rajah is mentioned, if it's to do with Factor VIII only, because he didn't use any Factor VIII but he did use large amounts of plasma and possibly cryoprecipitate, because it was a major cardiothoracic centre. He was a big user of blood, cryoprecipitate, plasma, et cetera but he never treated haemophilia or inherited bleeding disorders. So I'm surprised, you know, in what context his name is there. I think his name is in the context that a general supply of cryoprecipitate will be maintained, you know, for whatever treatment because -- and it's got lower risk of HIV.

SIR BRIAN LANGSTAFF: Thank you very much.

MS SCOTT: You have given evidence already that there was never a problem with cryoprecipitate but here there's a question about maintaining the supply. As far as you're aware, was that maintained?

unheat-treated NHS Factor VIII?

A. Well, as a general principle I always supported NHS products whatever, but, like I said, the perception was that if any -- or, reasonably big centre like us managed to use NHS products only, that we would actually cause a shortage and -- St James's Hospital did use more commercial than NHS. I think we were probably balanced but gradually going on to commercial. Gradually. But -- I don't know. I think, in a sense, we were proved right, that the commercial products were not as safe as people thought, you know.

Q. So --

A. Then, having said that, I think if you gave enough of the NHS stuff, if you give enough, then the advantage was lost because the number of donors went up.

Q. So at that time, in December '84, you preferred -- if you had to choose between NHS unheated and heated commercial, your preference was for NHS unheated. That's what this letter said --

A. Yes, but having said that, again, I think the heat treatment as it -- they began to show the benefits of heat treatment. You know, because the lower temperature then higher temperature and then wet. This is only a letter in one point in that history,

A. Oh, yes never had problems getting cryoprecipitate or fresh frozen plasma or platelets, you know. Very good Regional Blood Transfusion Centre actually.

Q. Can I then turn on to a meeting that took place in December 1984, which is at PARA0000008. This is a meeting held at the Blood Transfusion Service. You're present with Dr Swinburne, Dr Tovey, Dr Robinson and others. And we tried to identify who they were this morning.

It's a discussion about heat-treated Factor VIII or NHS untreated Factor VIII. That seems to be the discussion. It starts off:

"Although there is no proof or guarantee of its safety with regards to AIDS, it was agreed that on theoretical grounds heat-treated material was likely to be safe than non-heat treated material. However, Dr McEvoy and Dr Parapia agreed that they felt the NHS material was preferable to heat-treated American supplies. Dr Barnard and Dr Swinburne were in favour of heat-treated material from either source, but at the moment there is no hard evidence on which to base the choice."

So, just pausing there, do you remember this choice, as it were, at that time, between balancing on the one hand heat-treated commercial versus

you know.

Q. Yes. So what I'm asking is, can you remember why you came to that view at that time?

A. No, I couldn't tell you. But I wanted a balance, and we got that balance I think. Or some sort of balance.

Q. But was your view -- your preference for NHS unheated, was that based on the risk of the product rather than some other factor, like convenience, or other factors that we discussed today?

A. No, I think at that particular -- there may have been a question about heat treatment. I don't know. Maybe there had been cases of heat-treated commercial that had transmitted. I really can't remember the actual reasoning why I -- at that time, but you know, like I said, I think it -- dependent on individual patients and what we were treating and et cetera. But I didn't want the NHS Factor VIII to be stopped full stop, you know. I can't remember what the discussion -- the detailed discussion was actually.

Q. Then three conclusions are set out:

"After reviewing the financial position:

"1) It was agreed that no more untreated Factor VIII should be purchased. Existing stocks were low."

So that's a decision being made, no more

unheated Factor VIII:

"2) Centres would continue to use existing stocks of Elstree Factor VIII or cryoprecipitate."

Can you recall whether Leeds were using cryoprecipitate for people with haemophilia at that stage?

A. No, I think they were the same as us. I think they actually moved to commercial in a big way. But no, they weren't using cryoprecipitate for haemophiliacs. Maybe for von Willebrand's they were.

Q. Then:

"3) No further decisions can be made until after a meeting of Reference Centre Directors and Dr Lane have been held next week. It is hoped that this will result in a statement of policy, and, more details of the plan to heat treat NHS Factor VIII, and how this will affect the supply position in the next few months."

So it looks there like you've decided -- or, in spite of your preference for NHS unheated over commercial heated, you've decided: don't buy any more unheated and let's see what happens at this meeting because we can see there's going to be supply problems coming down the road. Then there's talk about what your requirements for the year are and usage to date

and so on, and that there will be a deficit -- so it's a deficit of 230,000 units which will need to be filled by purchasing heat-treated material.

So that, at the end of '84, seems that there isn't -- as you say, you would have required commercial product at that stage, you couldn't have got all your needs met by the NHS. Does that accord with your recollection?

A. Yes. I mean, there was always -- any meeting you went to, whether it was UKHCDO or local or regional, there was always a question of saying: NHS will not be able to meet your requirements. And therefore we must buy commercial.

What I haven't seen, and I'm quite amazed, is I've never seen documents where they said: well, this was what we manufactured, this is what we used, and this is what we carried over. You know, stock control statements. Never seen that with NHS material.

Q. So it was left to you to sort of guess, in a way, how much you could ask for, rather than them saying to you, "Look, this is what we've got and you can have this much of it"?

A. Exactly. There wasn't -- they weren't saying, "Look, this is what we're going to have and this is your entitlement, so that we can have a fair entitlement of

the NHS products spread out in the region."

Q. That would have been helpful to you because you may have been able to end up -- you may have ended up with more NHS product than you actually had?

A. Yes, we would have. I'm not quite sure whether the transfusion centre was geared up to keeping proper stock controls and looking at the dates and expiries and supplies and -- but, yes, I never had problem getting NHS material.

Q. Then, so just looking then at the document that came out of that meeting that you were waiting for. So you see, at the bottom of that letter, you have arranged a further meeting on 18 December, following the meeting of the UKHCDO. And Dr Lane -- and we know, and this is a document that the Inquiry has looked at on a number of occasions, but the document that came out of that meeting is HCDO0000270_007.

It's called the AIDS Advisory Document. That's a document that was in your papers and you received as a Centre Director, as I understand; is that right?

A. Yes.

Q. It sets out on page 2 a number of recommendations, beginning at the bottom of page 2:

"1. Concentrate is still needed ...

"2. Use DDAVP ..."

And then over the next page, please, Henry, it sets out haemophilia A recommendations under (3) and B under (4). And then says this:

"In individual patients there may ... be a choice. In general heated concentrate appears to be the recommendation of virologists consulted but individual Directors may wish to make up their own minds. This is particularly true of unheated NHS material. The evidence that heated US Factor VIII is safer than unheated NHS is debatable and some Directors may wish to continue using unheated NHS material until all supplies are heated. This is valid for carefully selected patients but must be on individual decision based on the assumption that somebody batches of NHS materials will be contaminated with HTLV-III."

So there it seems there's -- the same discussion that you were having back and forth in your meeting a few days earlier is being had in this meeting with UKHCDO?

A. This may have prompted me to perhaps move -- stop using unheated NHS material and use more of heated material.

Q. Because of the reference there to the assumption that some batches of NHS material will be contaminated by

HTLV-III?
A. That's right.
Q. So seeing that there so starkly may have altered your treatment policy. We'll look at some documents after that.
A. We always followed UKHCDO documents very closely.
Q. Although that's very much leaving it up to the individual director, isn't it?
A. Oh yes, always.
Q. Then what I think is the report from the -- then the meeting you planned was for 18 December, having received that document, and I think, as I understand it, the report from that is at PARA0000017.

This is a letter from Dr Swinburne to you dated 27 December 1984 and it starts by saying:

"I enclose some more comments for those of us who were not able to be present at the last meeting of Directors."

Have you got any recollection of whether or not this is the follow-up letter, if you like, from that 18 December meeting?
A. No.
Q. Do you recall whether you went to that 18 December meeting?

A. I would have gone.
Q. You would have gone.
A. I would have gone. I tried to go to all these meetings because, like I said, we were looking for answers and information.
Q. So, first of all, she says:

"Please note that heat-treated materials can only be supplied on a named patient basis."

She must there be referring to NHS heat-treated materials, mustn't she?
A. Well, I would think so because one of the things about heat-treated commercial material was we tried to use licensed products. If they were not licensed they would be on named-patient basis and that would have been -- you know, we would have ordered it and that would have been quite reasonable.

So I presume -- I don't know. I can't remember whether -- if it's heat-treated NHS material, obviously, that's very good, you know. That would be preferable to unheated NHS product. I mean, if it meant -- sorry, on a named-patient basis you know.
Q. Then she makes a reference to how that can be done and we'll come to some documents in relation to that in due course.

Then she says this:

"Because of the cost Dr Barnard and I have agreed to continue to use Elstree Factor VIII for heavy users converting to heat-treated NHS material as and when available."

So that seems to be -- she seems to be, on the basis of cost, deciding, although she prefers the heated commercial, to stick on the unheated NHS, for heavy users, in any event. Then:

"Patients using less than 20,000 units per annum, new patients, and small children will be given heat-treated commercial material or cryoprecipitate."

Your recollection is that, in fact, in Leeds they weren't treating with cryoprecipitate at this time?
A. They weren't using cryoprecipitate but it's interesting because their returns showed that two-thirds of the materials they used were actually commercial, not NHS. So this is not in line with their returns, you know.
Q. So this policy is something that you question whether it was followed?
A. But you have a document saying how much commercial they use and how much NHS.
Q. Then it says:

"We estimate that two thirds of our patients

will then be getting heat-treated material."

There's then a reference to the HTLV-III test, which I'll come back to.
A. Yes, it says there that two-thirds of the patients were getting heat-treated material, you know.
Q. Yes, commercial material or cryoprecipitate. Do you recall this --
SIR BRIAN LANGSTAFF: I think it actually says two-thirds will then be getting heat-treated material, in other words that leaves one-third would weren't? Whether the one-third were getting unheated NHS or, for that matter, unheated commercial or cryoprecipitate is not clear.
A. No.
MS SCOTT: So that seems to be the policy of Dr Swinburne following that meeting. Do you recollect whether or not that was something that you adopted as well, as a policy?
A. We didn't necessarily follow the same as Leeds did. We really acted quite independently but, obviously, within reason, you know, and what is available and what's best for patients.
Q. So the next document may assist you in answering that question if we could go please, Henry, to PARA0000016, this is a document from a little bit later on,

24 February 1986, from the Yorkshire Regional Health Authority National Blood Transfusion Service. That seems to be the full title of your local Blood Transfusion Centre where Dr Tovey was the director.

It records that a batch of unheat-treated Factor VIII was supplied on 22 January and then again on 5 February by the Regional Transfusion Centre to, amongst others, your centre. So that would suggest that, like Dr Swinburne, you were after December still using untreated NHS Factor VIII; does that sound right?

A. I honestly can't remember and I can't remember whether we used any of this. That would really depend on how much we returned, you know, for destruction. But, I mean, the question is we were supplied with it, whether -- how much we used I couldn't tell you.

Q. So that was my next question: do you recall the investigations that had to be undertaken following receipt of this letter about whether or not there had been an infection?

A. I honestly can't remember. But we would have followed the instruction to the letter. You know, we would have returned it. We might have returned all of it back, you know. I don't know how much of it we would have used. I doubt -- you know, once we were told

figures but, like it says, if they said return it for destruction we would have done it.

SIR BRIAN LANGSTAFF: If there was any left to return by then?

A. Yes, if there was. This was distributed on 1985. What's the --

SIR BRIAN LANGSTAFF: The date of this is a year later, 24 February 1986.

A. I couldn't tell you how much was used or not used. But it's a long time to have it, isn't it, it's a year.

SIR BRIAN LANGSTAFF: I think what counsel was asking you is if you hadn't returned it all, the last full big paragraph at the bottom of the page that we can see says:

"... secondly would you find out if any of your patients have been treated with any material from this batch."

A. We would have done that.

SIR BRIAN LANGSTAFF: So do you have any recollection of that is what she was asking.

A. I don't have any recollection, no. But we were -- we had a very good blood bank and we would have proceeded anyway, we would have followed it up.

MS SCOTT: So this letter suggests that you were sent

that heat-treated -- or if there was doubt on the unheat-treated we wouldn't have used it, you know.

Q. So following the letter at the meeting of 18 December, where Dr Swinburne sets out her policy that she will use unheated NHS factor, on the basis, it seems, of price, could the Blood Transfusion Service have simply sent you untreated Factor VIII --

A. They could have, yes.

Q. -- and you look at it and what would you do when you received that?

A. Well, they could have sent it, we would have it in stock but whether we used it or not I couldn't tell you because we had our own individual policies for patients, you know. But this would have been returned, you know, for destruction straight away but I couldn't tell you how much was and how much wasn't, you know.

SIR BRIAN LANGSTAFF: The dates may help. This is a letter in February 1986, and it looks as though the batch was distributed some time after 5 February 1985, that's about a year. Do you think it likely that if it did come to you, you would have used it within a year or would there have been any left to return, do you think?

A. I honestly -- I couldn't tell you without facts and

unheated Factor VIII in January 1985. I think you said, well, we might have been sent it even if we weren't going to use it.

A. Possible, yes.

Q. Would you then have sent it back? Would it not be likely that you would have sent that back if you weren't going to use it?

A. Well, at some -- sometimes we kept products because -- as a backup, you know, emergency, et cetera. It's good to have a good stock. I couldn't tell you how much was used and how much was not used and how much was kept back and -- but, really, unless I knew what or how we used it, I just couldn't tell you. There's no -- I can't recollect. That's too much detail.

Q. Then the next document, Henry, is PARA0000018. This is a document from 7 February 1985 and it's a letter from Dr Swinburne to Dr Tovey. Again, this was a letter that you had in your papers, and it starts by saying:

"The local directors have discussed the Elstree protocols and are not very interested in their offer of an interim heat-treated product likely to be available for only 2-3 months. They prefer to wait until April when a better product is promised. This also will need full evaluation for safety and

efficiency. Nevertheless I have applied to Elstree for heat-treated material for 10 heavy users to test their reaction."

So, first of all, can you recall what the Elstree protocols were?

A. No.

Q. Do you remember this --

A. I've never seen the Elstree protocol. Elstree protocols I can't recall -- obviously, it's there somewhere but I really can't recall Elstree had protocols.

Q. Do you recall making this decision? It looks like it's not just a decision of Dr Swinburne, it looks like a decision of the local directors but a joint decision not to accept interim heat-treated NHS product but instead to wait until, I think, April or thereabouts, when Elstree were saying that they could provide all of their product heat-treated. Do you recall the reasons why you came to that view?

A. No, but we didn't always to the same as Jimmy's, you know. We had the same status, whether it applied to Leeds only or to all of us, I can't recall, or whether we followed the -- if it's -- the instruction, you know.

Q. So you can't remember anything about that decision in

February not to have an interim heat-treated NHS product?

A. No, I cannot remember that at all. It seems unusual, doesn't it? I mean, it's obviously 30/40 years ago but I think I would have probably accepted that.

Q. You'd have accepted it; what do you mean by that?

A. Well, interim heat-treated NHS product would be very attractive, even if it's interim. But there were -- in those meetings, there were five or six directors, you know, and a lot followed Leeds' lead.

Q. She goes on at paragraph 2:

"In the interim all are willing to use the untreated BPL Factor VIII."

Then calculates what's needed. Then:

"Stocks should last till the end of March unless any users are found to be anti-HTLV-III negative and are refused by Elstree. In this case they will need to transfer to commercial material immediately."

Do you know what that refers to?

A. Sorry --

Q. Paragraph 3.

A. Where it says "heat-treated commercial"? No, I can't recall this but I'm a bit surprised in that heat-treated NHS material would have been a lot more attractive than unheated NHS material. This is

unusual. I can't even recall.

Q. Then it says "Bradford may need more commercial" -- I think that says heat-treated Factor VIII, and then it talks about distributing BPL heat-treated material via the blood transfusion service, and then ends with:

"There is still interest in a better version of cryoprecipitate, ie smaller volume."

Again can you recall what the interest in cryoprecipitate was, at that stage?

A. Interest in cryoprecipitate was minimal, you know. I'm sure in Yorkshire they didn't -- well, I shouldn't say -- certainly in Leeds/Bradford cryoprecipitate would not have been used for haemophiliacs.

Q. So looking at that at this distance, that letter seems -- that decision seems a surprising one to you?

A. There's still interest in a better version of cryoprecipitate, smaller volume. No, not from Bradford anyway. You know, when you're talking of seven or eight centres together, we were only one of them, so Dr Swinburne may have taken the majority view.

Q. But that decision there to turn down the interim heat-treated product and use unheated product seems, from this distance, a surprising one to you?

A. Very. Sounds very foreign to me. I think it would to

most people.

Q. Can you recall when Bradford, when your centre, switched completely to heat-treated materials?

A. I think we had evidence that, you know -- and obviously licensing was important but, as soon as we had information that heat treatment improved the concentrates, we would have moved on, you know.

Q. Here you are using commercial heat-treated concentrate, we can see in this letter. You're soon to be using unheated Factor VIII, NHS Factor VIII. Do you think that you would have moved over completely to heat-treated product once --

A. Heat-treated NHS.

Q. -- once you could get the NHS product?

A. Oh, yes we would have, yes. If it was available, we would have.

Q. Do you recall what, if any, steps were taken to deal with the unheated product that you already had once you had made the switch?

A. Well, if there was a recall it would have gone to BTS but before the recall I couldn't tell you what happened, whether we were using it on selected patients, I don't know, I couldn't tell you.

Q. So, let's say in April/May 1985, for the sake of argument, the centre goes over to heat-treated

product, do you, at that stage, recall all the unheated product that's out with people in home treatment? Can you recall whether any steps were taken of that nature to swap unheated product for heated product?

A. If there was indication that it was unsafe, then we would have recalled it. We would have brought it back. As I said, we only issued material that was outside the centre. We had them to come every month to exchange. They had to come every month. They would bring their old bottles and their needles and then they would be exchanged. So we would have been in touch and we never issued more than a month's supply for the severe. You know, it was very important that they didn't sit on supplies at home for long periods and it was mandatory that we reviewed -- one of the conditions for home treatment, to have material at home, was they must come to clinics every three months. If they didn't, their home treatment would have been stopped, you know. This made sure that people weren't holding the stuff, keeping it home, keeping expired material at home.

I think there was -- there is a letter somewhere about -- there was one patient who kept it for a long time because he wouldn't come to his clinic and he

wouldn't -- I know his name but I can't obviously name, you know.

Q. Can I just pick up one more point in this letter which is at the bottom of paragraph 1, Henry:

"Nevertheless I have applied to Elstree for heat-treated material for 10 heavy users to test their reaction."

I think that's a reference to getting heat-treated NHS product on a named patient basis, which you -- we have seen documents which suggest you put five patients forward at this stage for heat-treated NHS product; do you remember that?

A. No, but it's obvious you have got information.

Q. Yes, well, I can show you.

Henry, it's BPLL0010619.

A. As I said, heat-treated NHS was very attractive, you know.

Q. The question really was whether or not you recall whether or not these patients were -- like Dr Swinburne did -- heavy users, being put forward to -- Dr Swinburne says -- test their reaction, or whether they were, you know, previously untreated patients?

A. Well, if they were untreated patients, we would prefer them to go on a trial basis -- no, "trial" is the

wrong word, because you're not trying, but we would have wanted to monitor them, you know, have a protocol et cetera. It would be a PUPs -- you know, what you call PUPs, previously untreated patient. So this -- these, I presume, would already have been either on NHS or they were heavy users. But I can't tell you -- I mean, what goes further down on that letter? Does it say?

Q. It doesn't say --

A. It just says "following five patients".

Q. No --

A. But those five patients would be previously treated. If they were untreated they would be -- we would possibly use the same thing, but they would come under special protocols.

Q. Yes, so I think you entered one patient later on into the study, and that was in 19 --

A. This was the product they were talking about.

Q. It was the same product. It was the 8Y product.

A. Yes, so we were -- so that is a very special situation, you know. That was the 8Y study which Dr Rizza I think was -- I think there was a few centres taking part but I think it came from Oxford, that study.

But previously untreated patients, very, very

important, you know, because you follow the protocol to make sure that -- you know, whether the new product was as safe as people said it was.

Q. Can I just take you to one passage in your witness statement.

Henry, it is WITN0785003.

And and it's page 8, and it's the response to question 31. And you say, in response to a question, what steps did you take when you knew there might be an association between AIDS and use of blood products, and you say:

"We discontinued using blood products that we felt had the possible risks of infections of HIV or Hepatitis C. NHS and commercial blood products were used on the basis of reassurances given by the suppliers."

What are you describing there?

A. You know, it actually should say -- the "possible risks", it should say "probable risks". Because there was a possible risk with all products.

Q. Yes.

A. It should have said "probable risks". Or we tried to use products with the least possibility of infections.

Q. So how did you assess whether or not you should stop a product because of probable risks?

A. Very difficult.
Q. Was it effectively when you got a letter saying "This batch is infected"?
A. The information would have come from different sources. One is our own source. So if anybody got infected with a product we used -- and I think you've got some evidence there -- that we were very quick to point out.

The other one was if any of the neighbouring centres or if UKHCDO or we were informed by any of the centres within or from the regional, then there was obviously -- there was an obligation on the companies or whoever was producing this, they would have to inform us immediately if we had their product and there was a possibility that it transmitted infection.

But as soon as we thought that there was even the slightest possibility now, then we would withdraw it, you know.
Q. What do you mean when you say, "NHS and commercial blood products were used on the basis of reassurances given by the suppliers"?
A. Well, we needed reassurances all the time because -- you must remember, that we had to -- even now, with any medicine that we use, we've got to be aware what that medicine is and what are the side effects

et cetera and what are the benefits and so on. We really needed that in order to avoid litigation then, you know, that we didn't knowingly give something that shouldn't have been given.
Q. So what were you asking for? They can't have been giving -- they weren't giving you reassurances, were they, that the product was virus-free?
A. No, nobody did that. Even now.
Q. So what kind of reassurances were they giving you?
A. Well, that -- really I think there is a letter when I first ordered materials to reassure me that they were following the FDA rules.
Q. I see. So, you spoke about this this morning, yes.
A. I think, as far as they could give reassurances, that -- you know, that they are following all the regulations, et cetera. But on a named patient basis it's a bit different, you know.

And obviously knowing that they were licensed was important, because that gives some protection to the directors as well.
Q. Henry, can we have HCDO0000321_002.

I hope this is -- yes, it is -- the 1986 return. And it shows that you treated 26 patients that year and it sets out that you have actually treated with cryoprecipitate in hospital for somebody with

haemophilia A, NHS factor and then a number of different commercial factor products.

Is this return a reflection of that policy, do you think, the reason there are so many different products being used there?
A. Yes, it would be, really. I think these are the products that Dr Swinburne had mentioned that they were contracting with, you know. It's the same products from the Regional Transfusion Centre. But we tried to keep people on the same product as far as we could. For obvious reasons, you know. Even for reasons of inhibitors and so on, you know. They weren't always identical so it was important that if there were going to be side effects or inhibitors or infection that we could identify the batches.

But you are right that there's a lot more companies there than that was few years ago. And we're also treating more people there and using more product, you know.
MS SCOTT: Sir, I'm going to come on to a new topic now, and I note the time.
SIR BRIAN LANGSTAFF: Yes. We will take a break. How long do you think you might need?
MS SCOTT: For a break?
SIR BRIAN LANGSTAFF: Yes.

MS SCOTT: 20 minutes.
SIR BRIAN LANGSTAFF: Will you be likely to be talking to the representatives of -- the legal reps?
MS SCOTT: Yes.
SIR BRIAN LANGSTAFF: I will give you a bit longer so that you can pick up any questions that Core Participants might wish to ask. So shall we say be back at 3.30.
(2.57 pm)

(A short break)

(3.30 pm)
MS SCOTT: I'm going to ask you some questions about testing for HIV. So, Henry, can we have PARA0000017, which is a document we have already looked at but it really is a memory prompt. So this is a document we looked at a letter from Dr Swinburne to you 27 December 1984. Henry, it's the last paragraph.

"The PHLS are now able to screen haemophiliacs for HTLV-III antibodies. A sample should be taken from each patient prior to starting heat-treated material. In due course all patients should be screened although the interpretation of the test in present circumstances is not yet clear and the results should remain confidential."

So, first of all, just on timing, looking at that, does that prompt your memory at all as to when

you think you might have carried out HIV testing on your patients?
A. As soon as the tests were available we were testing. So if it was available then, then we were doing it.
Q. Did you tell your patients in advance that they were going to be tested for HIV?
A. Not in advance but when they came to the clinic, and so on, when they had blood tests we would have told them then. You see, also at that time there was a very strong pressure that they must be counselled before they had a test. So we had a counsellor, we had the clinic, so we would have arranged for them to be seen, counselled and then have the tests.
Q. So you weren't testing off stored samples, you were testing off samples you took in clinic?
A. Yes.
Q. You were informing patients when they came in that the blood test was going to be used for an HIV test?
A. Yes. Memory is vague but it wouldn't even surprise me if we got them to sign a piece of paper that they had been counselled and they are having the test. There was a lot of pressure at that time from Terrence Higgins Trust about -- that they shouldn't be tested at all in Bradford. There was a lot of -- there was a movement that you mustn't test people. People

mustn't come forward.
Q. Because? Did you understand what the reason for that was?
A. Well, their reasons was it was to do with freedom of individuals and if you're going to have a test that you can't do anything about then it's discriminatory to pick out people for the test. But that's not why we were doing it for haemophilia, that was a different reason.
Q. Do you recall any of your patients saying they didn't want to have the test?
A. No.
Q. Everybody wanted to have it or --
A. Yes. Yes, everyone who had blood products had the test, I think, initially.
Q. When you say the advice was that you should be counselled before you had the test, what did you understand that to mean and what was the practice that you put in place?
A. The counselling would have been in -- you are saying why were we doing it?
Q. Yes, what did you understand you were supposed to be doing and what did you actually do?
A. Well, when the test was there people knew about HIV so it was almost a routine test not to show that they've

got AIDS but to do the antibody test whose interpretation wasn't totally clear at that time but, in the same way as we did other tests, but that we wanted to know whether they had been exposed to the virus, you know, which was important for us to know but it might be important for them to know, you know.
But also there was a question of advising about how they go about with people nearby, you know, what their relationships are like and --
Q. So that was counselling before they had the test. You would give them some information about --
A. That's right.
Q. -- infecting partners, and so on?
A. Well, I think we would have talked about that probably but, you know, we didn't know the significance, total significance of the antibody test. That was one of the reasons why there was objection to the test, you know. I mean, I could see some sense in it but obviously now we can see better sense, you know.
Q. So having got the consent of your patients, sent the tests off, the results come back, what do you do then in terms of informing patients about the test results?
A. People who would have had the test were the ones that would have come every three months. These were starting with the severe haemophilics, et cetera, and,

you know, we tried to have proper clinics where the counsellor would be there, you know, or social worker, and Pauline Sharp, and so on. So they would have been seen but they would be first seen by me to give the test and then Sister Sharp would probably be there with me and then passed on next door, or whenever, to spend some time with Andrea.
Q. Do you remember that, can you actually remember that?
A. Yes, I can remember.
Q. You can remember that process. Can you recall whether --
A. Difficult times, you know.
Q. Yes. Can you recall whether you brought people in for special appointments or whether you did it in your regular three-monthly appointment?
A. It depended on -- it was a time factor thing. If the clinics were going to be very busy we made extra time. Andrea could see them in her own time, in her own environment, you know, but my work was done in the clinics. Patients were spaced out, you know, quite reasonably and plenty of time given. But they were followed up whether by Sister Sharp or by Andrea. It wasn't just a five-minute thing that finished, you know.
Q. Just before I come on, because I want to ask you some

questions about the follow-up and the counselling and so on, can we just return back to this document on the screen. It's the same paragraph, Henry. The last sentence there -- so this is Dr Swinburne telling you that the tests are available, and she says "interpretation of the test [is unclear]" and you've given evidence about that, and "the results should remain confidential".

Do you know what she meant there?

A. I don't know what she means but the results were confidential. They remain in the domain of the hospital records. But the results came from public health laboratories.

Q. But you have just told us it doesn't mean it remained confidential from the patient?

A. No, no, no. Not at all, no. That's why I don't know what she means. It certainly shouldn't remain confidential from the patient. The ownership of all results are with the patient, it's their results.

Q. Then I interrupted you, you were talking about the counselling that was available to patients. So you have described how they had some pre-test counselling, and then there was counselling available when they were given their results, and then you were talking about follow up. Can you just explain to us what

follow-up was available for your patients who had been infected by HTLV-III?

A. Well, it often raised more questions than answers. That was the problem. So they needed support. They needed more explanation sometimes, and they were fed with information in the media all the time. There was -- as you know, the popular press was full of all sorts of speculations and accusations and -- you know, there were some groups that really felt paranoid about what was said about them, you know.

Q. So were you able to -- were people able to have, say, a course of psychotherapeutic counselling through your centre; was that available to them?

A. Yes, but we also had a psychologist called Dr Dawson, who was doing some research where the university was also supported with the counselling. He was a psychologist.

But we tried to get proper psychologist, hospital psychologist, for them to support us and that was very intermittent and it didn't go anywhere.

Q. You did some research, I understand, or at least you had ethical approval for a study into people with haemophilia to identify their emotional and psychosocial needs in October 1985, do you recall that with, Dr Hunt?

A. That was with Dr Dawson the psychologist.

Q. Okay. So that is who you are referring to?

A. There were quite interesting findings which haven't been explored that much, as they should have, because what we found was people who had psychometric testing when they got HIV or HTLV-III, that the psychometric testing was affected, that it did affect their mental performance. We found this with leukaemia, with chemotherapy and all sorts, but Dr Dawson -- I don't know whether he became ill or he had to leave.

Q. So you did complete that research and produced a paper did you?

A. Only abstracts. It never got published as a paper but, I mean, it applies as much now with Covid, you know, that you do psychometric testing now and then after Covid people are finding big differences, you know, that it actually does reduce your IQ, et cetera, you know.

Q. So your patients had access to a psychologist and counsellor through --

A. Counsellor primarily but we also had support from a psychologist.

Q. -- your service? Did you test partners and family members?

A. Not routinely, no --

Q. So what circumstances --

A. -- but if we were requested.

Q. If it was requested you would test?

A. We would test, yes. Interestingly, when we did test we didn't find any partners that were positive.

Q. Just on numbers that were infected, we've only got one document and I don't know if you can help me interpret it, it's BTHT0000002. So this is the covering letter and it's enclosing statistics for patients treated between April 1991 and March 1992 inclusive, so a little bit after these years we're talking about when the tests took place. If we scroll through the document at page 2 please, Henry -- maybe page -- that's better.

You can see here it says "HIV/AIDS cases", then it sets out the period, "In-patient summary by District of Residence/Consultant", and then it has "Airedale" and then your name and "2". Then if we go over two pages it has "Bradford", and we can see there "Minford 1", and your name, 48. District total for Bradford is 53, and so on. So you go through the document with all the different areas and the consultants with the numbers of HIV patients is set out there.

Is that a document you are familiar with?

A. No. But because when HIV tests came along and we had counselling and testing, and so on, there were no HIV experts in the district. There were none appointed for obvious reasons, and the largest population that was positive was haemophilia and because we had a full setup we attracted non-haemophiliacs, non-bleeders who came for testing.
Q. To the centre?
A. To the centre, yes, we were referred. And because they didn't have anywhere else to go, we were testing them, et cetera, but also in the private sector people used to come for testing, you know, at Yorkshire clinic, and I used to see them.
So these are mixed up.
Q. Because I couldn't make sense of the numbers because the numbers, according to this document, of your patients with HIV between '91 and '92 is 71, and you've told us that actually you had 40 patients with haemophilia, so ...
A. These are mixed up with all of these from other --
Q. Sorry. Were you treating these patients for their HIV?
A. No.
Q. You were the consultant who was testing them?
A. Yes. It was counselling and testing them. So we

offered that facility. But if they were positive they would be referred on. And it mentions the GU specialist, Mohanty. For some reason he's only got one there, I can't understand that. But we used to refer -- there was another GU specialist, and there was obviously -- there were also people in Leeds who were considered experts, that were actually appointed for that function.
Q. So you never prescribed anyone AZT, for example?
A. No, no. But we did have patients with AZT then but I didn't -- no, it was something that I tried to avoid, is -- trying to become an HIV specialist. Although I was the only one at the time. But within a few years they appointed specialists, you know.
Q. Were any of your patients who had the rarer blood disorders that you were speaking about this morning, were any of them infected?
A. No.
Q. Only people with haemophilia that you were treating?
A. And von Willebrand's, I think.
Q. And von Willebrand's.
A. And kids. But no, none others. Which is interesting, because they all -- a lot of them used NHS material for one reason or the other.
Q. Did you do any work to try to establish when

seroconversion happened, i.e. on previous stored samples?
A. We didn't check stored samples but I think there are documents which says they could -- they might have got infected in '78 to '79. Some other people had done this work. I think It was Peter Kernoff who had looked at previous samples, to old samples, and found infected people in '78/'79 samples.
Q. You never did that with your patients?
A. No.
Q. Did your patients know that their test results were being shared with UKHCDO? Is that something they were aware of? Do you think you discussed that with them?
A. Well, they were anonymised if they were shared. They were just numbers. So it wasn't that we shared the patient details. We shared numbers but we didn't share any patient details. So it wasn't their information that was being shared, it was just statistical numbers. As far as I remember.
Q. Then moving on then to HCV testing, when that came in, again, can you recall when you undertook HCV testing, hepatitis C testing, for your patients?
A. As soon as it was available from PHLS, Public Health Laboratories, in Leeds, we started testing them. Would it be '91? I don't know.

Q. Probably '91. We don't have the precise date.
SIR BRIAN LANGSTAFF: There were tests which were available from 1990 onwards. Though it was regularly used to screen transfusion -- blood for transfusion -- from September 1991, there is some evidence I think that one test or another was used on a trial or *ad hoc* basis at various centres in between those two dates. That's not much help.
A. No, but as soon as it was available to us -- you know, as soon as Public Health said yes, you know, we started -- initially antibody test but the more important was the combined with the PCR. You know, whether there was active virus or not.
MS SCOTT: Again, in terms of the process, what was the process that you went through when you were testing your patients for HCV? Did you inform them or ask them whether or not they wanted to have a test?
A. Well, they were regularly having liver function tests, because if they had abnormal liver function, they knew that I was monitoring them. So when this test came along, this was just an added test to the -- as it was for liver function, you know.
I can't honestly remember whether -- you see, quite often they would have the test before seeing me in the clinic. So they had the blood test done and

I saw them in the clinic, I would tell them what was done. So -- you know, I can't remember which way it was. But certainly as the results came in, they were all discussed, including the liver function tests.

Q. So it may be that their consent wasn't obtained before having the test specifically to the hepatitis C test?

A. That's a possibility. But it was in combination with the liver function tests. You know, but when we had the results, the results were never kept from them.

Q. Then as soon as you got the results back, you shared those with the patient, presumably at their next appointment?

A. Oh, yes. As soon as we had the results.

And I never had a single person who objected, by the way.

Q. Who objected to?

A. Having had the antibody test done, for the hepatitis C. Not one. Like I said, it's -- sharing information was one of our strengths, of the clinic.

Q. Did you test all of your patients for hepatitis C?

A. I think ultimately we -- all the patients who received blood products we did, because there was also this question that if they converted, if any of them converted, then the implication would be the batches of Factor VIII that they were getting.

So, yes, if you were looking for abnormal liver functions and a positive hepatitis C test, that was because we were looking for -- to diagnose hepatitis. But if they were negative, then it said that the products they received did not contain the hepatitis virus. So there was benefit in having both, you know.

Q. So, following the tests, were you carrying out sort of look-back exercises almost to look at the products they have used over the years?

A. Immediately, if -- if there was an element where it would help them to trace which products. Sometimes it was impossible because if they'd had blood products for ten, 15, 20 years, there's no benefit. But if they only had one or two products, then we can --

Q. Then you would have gone back and done --

A. Oh yes. That's -- that's quite serious.

Q. You did do that? Do you recall doing that?

A. We would do that, yes, absolutely.

Q. Because in your witness statement -- I only ask you that question about whether you tested all your patients because in your witness statement you suggest that only ten of your patients, you think, as a guess -- your best guess, best estimate -- that only ten of your patients were HCV positive?

A. Yes, there weren't that many really. There may have

been more. I can't -- I really can't remember.

Q. It's a slightly surprising evidence because I think -- is it right that you had approximately around sort of 20 to 25 regularly treated severe patients?

A. That's right.

Q. Do you think that some of those tests came back negative for hepatitis C?

A. It's possible. But ten seems quite low, doesn't it, if they had a lot of Factor VIII, you know?

Q. So you don't recollect being surprised when the results came back and thinking: oh, somebody who has had a lot of factor product in their life has come back negative. That's not something you remember?

A. I can't recall that actually. But I think heavily treated haemophiliacs, all of them had become hepatitis -- had non-A, non-B, and then hepatitis C positive, you know. I think there may have been a mistake in typing or whatever, but ten seems very low.

Q. Again, did you treat -- or, did you test, sorry, family members for hepatitis C? Do you recall doing that?

A. No, no, we never had to. Certainly we wouldn't do it routinely but we -- we never had a relative that was ill, somebody that was ill that we had to test, you

know.

Q. Can you recall what advice was given to patients if they tested positive, about lifestyle and transmission of the virus and so on?

A. They had to be warned that it could be transmitted sexually. You know, body fluids or whatever. That was very difficult actually because -- you know, when you've got life-long partners and they have had relations for many years and then to be told -- I think that was hard, actually.

But as far as -- I think we tried to tell people that this was -- we were obliged to tell, you know.

Q. Would you have recorded those sorts of discussions in medical notes?

A. I don't think we would have recorded in full. Maybe it would have just said "discussed" or "counselled". And this was also supported by our staff by the way.

Q. Was written material given to patients about lifestyle and transmission and so on?

A. We had written material, printed material.

Q. For hepatitis C?

A. Yes.

Q. And for HIV?

A. Yes. We had -- as far as possible, whenever we got printed material available from whatever source,

including Haemophilia Society, that -- we made that available. It made our job easier.

Q. Henry, can I have PARA0000006.

This is a note again a letter from Dr Swinburne to you, dated 13 May 1985, headed "AIDS". And it starts:

"The Regional Medical Committee has set up an *ad hoc* working party on AIDS."

We can just see there the membership does not include you but it does include Dr Swinburne and Dr Tovey.

And then going back to the letter:

"Recommendations based on the interim guidelines are being formulated and documents produced by other bodies such as the Royal College of Nursing and Haemophilia Society are being taken into account."

Just pausing there, do you know what the interim guidelines she's referring to there are?

A. Well, I can't remember but you are going to show them to me, I think.

Q. I'm not actually, but I am just going to show you what -- she says:

"I have made notes on those proposals which have a bearing on haemophilia and suggest that before any of these proposals is incorporated into guidelines,

Directors should make their own views and policies known ..." and then says where to forward them to.

Then, Henry, if we go over the page, she sets out the ones that are relevant to haemophilia, and we have:

"1. General practitioners should be notified of the results of tests of anti-HTLV-III."

Do you recall what your practice was in relation to informing GPs of diagnoses of HTLV-III and/or hepatitis C?

A. Whenever any patients came to the clinic we did a letter to the general practitioner and giving results and, you know -- so we didn't keep things back from general practitioner.

Q. Is that something, particularly in relation to HTLV-III, that you would have spoken to the patient about and explained what you were doing or sought their consent or come to an agreement about or is that something you just did anyway, as a matter of course?

A. No, patients knew that we wrote to the general practitioner each time. We sent a letter with the results. Quite standard practice and they knew that, you know. There's no problem there at all.

Q. Then secondly:

"During counselling patients should be advised

to inform their dentists of their anti-HTLV-III status."

Again, was that your practice to advise your patients to inform the dentist?

A. A lot of them didn't have dentists because dentists wouldn't come anywhere near, so we had our own dentist.

Q. Your own dentist would have known about their status?

A. That's right. It's interesting it mentions Mr Mason, oral surgeon. He was very happy to -- not very happy, that's the wrong thing, but he would treat our patients if the need arose, you know, but after they had seen Hugh McCarthy, the community dental surgeon.

Q. Then slightly out of turn on this subject but, anyway, a point on this document, if we go to the second half of paragraph 3, where it starts:

"The question of labelling case notes was controversial but there should be a clear indication of the patients' anti-HTLV-III status in the case notes. External labelling, wording specifically mentioning AIDS or hepatitis could give rise to problems from loss of confidentiality."

What was your practice in relation to any external markers on someone's file about their infected status?

A. There's a lot of discussion on this because what we were required was to put not "HTLV-III" or anything but "infection risk" labels on all laboratory requests, laboratory bottles, on the green cards, and we were asked to put it on the case notes, as well, but not HTLV-III, just infection risk, and that infection risk could have applied to anybody in the hospital, with even hepatitis carriage or any other -- a lot of debate on that but this is what we were required to do and the reasons are obvious, especially in the laboratory where they are handling samples. They had to know.

Q. So that's in relation to samples but, in relation to the actual case notes, so recommendation is obviously inside the case notes there must be a record of the infection status but external labelling, what was your practice for external labelling on someone's notes?

A. No, I think it said -- I think it wasn't danger of infection, I think it said something in the area of "infection risk".

Q. On the actual hospital notes?

A. Yes. But that applied not just to -- that applied right across the hospital.

Q. Yes. Then returning then to those infected with HCV, you've described the counselling available for those

that are infected by HIV. By the time we get to testing in the 90s what counselling, if any, was available for people that got back positive diagnoses for HCV?

A. We followed patients with HCV regularly with blood tests because I think -- I don't know when the PCR came in that was quite important and we had to sort of work out, you know, how -- what sort of HCV they had. At that sort of time we would refer it to the infectious disease consultant or the pathologists, you know, one of the two.

Q. If there was a positive test they would go off and be treated by somebody else?

A. If the PCR was positive.

Q. So would any counselling and --

A. That department would then have to look at the liver side of things.

Q. Would any counselling and psychosocial requirements that the patients had as a result of their HCV status then be dealt with by that department rather than by your own?

A. We'd pass it on, yes, because their own, obviously, departments and staff, and so on.

Q. So the centre wasn't providing any counselling for HCV patients at that time?

A. It depends what you call counselling. We did talk, we did talk to them about it.

Q. You did talk to patients. But in the way you described the more formal psychologist and counsellor for HIV, that wasn't available in the 1990s?

A. We probably don't -- I don't think we did that.

Q. So, again, you have described that anyone that had a positive result was treated elsewhere. So do I understand from that you wouldn't have ever prescribed any medication for HCV like interferon or anything of that sort?

A. Never. Although, I mean we used interferon on haematological malignancies but I never treated hepatitis C.

Q. In your witness statement you describe some of -- you describe -- you were asked some questions about the relationship between pharmaceutical companies and clinical centre directors or clinical staff, and you describe some of the hospitality given by the pharmaceutical directors as extravagant. Can you just describe for us what you meant by that?

A. When we went to conferences, meetings and so on which -- pharmaceutical companies were very important for us to attend meetings, for all the directors, but obviously there were different grades. So the

directors that were most closely associated with companies would stay in the conference hotels and have five-star, et cetera, et cetera, and you could see that they were -- then there were gradations and you could see that as you went lower down the usage of Factor VIII in numbers or type of centre you were, then you may have to go into three-star and four-star hotels, and you could see the dinners, et cetera, et cetera. There was quite a big difference on hospitality that people got.

I don't know how far do you want me to tell you about these things?

Q. Well --

A. What do you want to know?

Q. Is that the extent of the extravagant hospitality you were talking about or were there more extravagant hospitality that you had in mind when you said that?

A. Well, I'm sure there was. The bigger -- the centres that were more -- were nearer working with pharmaceutical companies and so on, people who used more of the product had a lot of support for their departments. And there were individuals being employed as consultants. I know at least one who is still working as a consultant to one of the pharmaceutical companies. There were research grants.

There was all sorts of available monies from pharmaceutical companies.

But in terms of meetings, we all needed the meetings, whether it was local, national or international, whatever, because that was the only way we could send our staff. There was no money in the NHS. There was money for me, as a consultant. I could ask for the post graduate funding. You know, I could get money. But if I wanted our nurse or people to go, laboratory staff, I had to ask around to try and get backing, you know.

Now, it's sad that, it's unfortunate, because I think even now things haven't changed that much, although now they would have to declare it. And some things would be unacceptable now. What -- if the gifts went above a certain level, you know, it wouldn't be acceptable at all. But at that time it was accepted practice. It was normal practice.

Q. Did that at the time cause you any concern? Were you ever concerned about how close some directors were to the pharmaceutical companies?

A. Only in that this was -- some of them were the same directors who were advising the Government, or on reference -- there were reference directors who were in committees that, you know, were recommending.

I mean, we wanted honest advice and, you know, it sort of made us think: well, you know, is this purely unbiased or not? You know. I think it was unbiased. I think we got very good guidelines from UKHCDO. But it wasn't pleasant visibly to see people not declaring their interest, you know. Which they would have to now. You know, they wouldn't be allowed to do it. It would be scandalous. But at that time it was -- seemed acceptable practice to be -- a Reference Centre Director to be on committees that recommended the use of Factor VIII, and they would be the advisers to the Government. And these are people are paid by the National Health Service, employed by the National Health Service.

Q. Meanwhile taking --

A. It's a bit strange, you know.

Q. Meanwhile having extravagant hospitality and gifts and so on from the very companies that they are potentially putting forward as to the Government.

A. Yes, it was -- it felt a bit strange but I -- we took hospitality too, you know, but obviously not -- I -- we took it largely for our staff.

But remember, things are still most -- if you look at all the educational meetings and so on for general practitioners and so on, they are still backed

by pharmaceutical companies to promote their own products. So they must have been doing it to promote their products.

And I think I've mentioned that we had to talk to representatives and so on, and we had more visits from the pharmaceutical companies representatives than we ever had from BPL, which was, again, very sad, because they should have been acting -- if they were going to act like a pharmaceutical company, they should have had a budget for it and, you know, promote et cetera, et cetera. If they were to be, like, a part of Blood Transfusion Service, then they should have been in the same place as the way you use blood transfusion, et cetera. But I don't think they had -- they were not business-like enough to be able to promote themselves. It felt very strange and sad for them. I felt sad for them that they were not able to compete on equal footing, you know, with multi-national companies.

Q. Did anyone from a pharmaceutical company ever try to seek to influence your decisions about which products to buy?

A. Well, they were all trying to market their products, so obviously they had to say nice things about their products, but we had to prod and find out the

actual -- and seek reassurances, you know, seek what the products were about, you know.

Q. So they were marketing themselves to you during visits. But would it ever go beyond that?

A. No, because we would not be influenced, because at the end of the day it was our head, you know -- it was our necks. No. But I would have liked more discussions with BPL, which -- there was very -- I complained officially that: why am I not getting visits from BPL? That I want to discuss things. Because they were not only doing Factor VIII, they were doing immunoglobulins as well as a few other products, you know, NTDs.

Q. I have had some questions from Core Participants to ask you. They are going to be dotting around a bit on subject matter.

The first one is in relation to -- it's really the sort of culture of the UKHCDO, that organisation, and particularly to get to your perspective, as someone who wasn't in the inner circle and wasn't -- was in a relatively small Reference Centre.

There was clearly a hierarchy, because there was the inner circle, as you described it, of Reference Centres and so on. Was it a forum in which, at annual general meetings, for example, you could challenge

authority figures, Professor Bloom, for example, and it was -- was there a culture of open debate there?

A. It's open debate with over 100 people there, so you couldn't call it -- it would be very difficult to debate anything.

Q. Yes.

A. I think -- I mean, me being quite young and early, I found it -- I would have found it intimidating to try and speak out. But they were very good -- quite a few of them were very, very good, very -- full of integrity. They were people I could listen to. You know, especially people like Charles Rizza, Peter Kernoff and so on, you know.

But the culture of -- I do not know of any illness/disease where you got to hit a number to be a Reference Centre. I mean, do we have a system that you have got to hit 40 Covids to be a Covid Reference Centre? You know, here you had a system where -- we had a full comprehensive centre, we had more Asian bleeders because of the practice of consanguinity and so on, because we didn't have 40 haemophiliacs -- I think it was 30 or 40 -- we can't be a reference centre. Do we know of anywhere where it's organised in the same way and it's -- you could predict which first places were going to be the Reference Centres,

mostly in the south-east?

People had to move. Haemophiliacs had to move towns. A lot of them tried to live near Oxford, you know. Do you have to move town to get a Reference Centre? Half the patients, haemophiliacs were treated outside the Reference Centres. A system based on districts and areas would be far better. And it was all about resources and it's, like I said, the inner circle. It was a club. Like Geoff Savidge said, it's a club. You know, he called it a club.

Q. You would agree with that?

A. Well, they did a lot of good work. I'm not trying to -- but I think it could have been organised a bit better but I've never known anywhere where it says you have got to hit a number and, bingo, you know, you can apply. Because if you're one short, you don't have enough experience. You know, it's crazy.

And that system is still there by the way, you know.

But I think now we've moved on. We've got -- all right, haemophilia was very important, was one of the first bleeding disorders. But now we've got other bleeding disorders far in excess, and we've got thrombosis and so on. You know, we need to move on. And Resource Centres that are good, that are

excellent, but call them by something else. Perhaps "Centres of Excellence". You know, if you have renal dialysis centres -- you know, you have cardiothoracic centres, et cetera, you should have haemostasis and thrombosis centres, you know, to be more equitable. But not based on hitting a number and, you know, having friends in the right places and the right people to -- sorry, I'm going on a bit.

Q. And Government money following that decision?

A. That's right. That's what it was about: resources. It was all about resources, either from Government or companies or research or whatever, you know.

But, like I said, they have done -- there are some people of absolute integrity and they have done some good work. But a lot of divided opinion, a lot of divided interests in there. But I think we should learn from all this, you know.

Q. Going back to the discussion we had earlier about informing patients about the risk of AIDS, arising from treatment with factor products, you said that you weren't offering that information to patients but if patients were coming to you with concerns about it then you think you would have discussed it with them. The question is whether you would expect to have recorded those discussions in their medical notes. Do

you think that that's the sort of thing you would record in medical notes, in their clinical notes?

A. I think that at first patients seemed to be very knowledgeable. They knew what -- the risk of AIDS, et cetera. So when they came we made time to talk to them and so did Sister Sharp, and so on. So it wasn't a question of them having to ask, specifically. The information would be shared. So before AIDS, we were testing for it, the topic would have arisen, after testing definitely we would have talked, you know, there would be counselling and testing.

Q. Would you have recorded that in the notes?

A. I think that -- either it would be recorded by me or staff or -- but there could be also in the nursing notes. You know, Sister Sharp kept the nursing notes which may have been more complete than -- and obviously if they did see the counsellor, and so on they would be there but she left many years ago. But we were not allowed to do HIV testing without counselling and then to sign that, you know, they have been counselled and they agreed to the test.

Q. But before the testing, if you were having a discussion about AIDS and the risk of AIDS, would you personally, in your practice, would you have expected yourself to record in the notes a record that

that conversation's taken place?

A. Well, they couldn't have the test without signing that they were counselled.

Q. No, this is not the test, not the test.

A. No, not this -- I can't remember whether, you know -- I honestly can't -- I mean, I think good medical practice would be to record it. That would be good medical practice. I think I might have, I might not have. I can't remember. But good medical practice would have said that you should record.

Q. Another question related to this topic is to ask you this, would you accept that by not informing patients about the risk of AIDS from blood products that the patients lose the opportunity to take steps to prevent onward infection of their families of HTLV-III, HIV virus, if they had it?

A. I've never deliberately not told patients about risks of AIDS from blood products. Like I said, most of them were well informed anyway and if we knew that there was risks then that would have been discussed at the clinic. That would have been discussed at some point.

But, you know, haemophilia care it's very live. There's interactions going on all the time. There are comings and goings all the times, there's meeting

nurses, doctors, treatments and these are happening all the time. It would be very unusual that we would have kept knowledge that we had from patients deliberately. No, we wouldn't.

Q. So I had understood your earlier evidence to be that before the test came online, as it were, for HIV you weren't routinely telling patients about the risk of AIDS from factor concentrates?

A. No, we wouldn't have been telling, because it was still in flux. There were conflicting views but if it was brought up, we would certainly -- I would certainly tell the state of the art knowledge. I would tell the patients, you know. But I wouldn't give a false reassurance, as you saw in the letter from Society, you know.

MS SCOTT: I think those are all the questions that I have and I have had from CPs, from Core Participants, as well.

Sir, unless there's --

SIR BRIAN LANGSTAFF: Yes, well let me just ask one or two questions, if I may.

I wonder if we can go back to 0020293_0009. This is the diagram showing the comprehensive care model from 1987, I think it is. It's HSOC0020293. Can we go to page 9 of that? It's the wrong reference

I've got here, I'm sorry. My apologies.

MS SCOTT: Try page 8.

SIR BRIAN LANGSTAFF: Thank you. Could we just have a closer look at the diagram, thank you. Now, this is your centre in 1987?

A. Yes.

SIR BRIAN LANGSTAFF: In the case of anyone who was known to be infected with HIV, there is no reference here to there having been a GU consultant or someone expert in AIDS, apart from yourself, perhaps; where would they go?

A. There was no GU. There was no HIV expert at that time. I was the first one who suddenly inherited or had all these patients with HIV.

SIR BRIAN LANGSTAFF: So that would be you?

A. Yes, it would be. But only for a short while.

SIR BRIAN LANGSTAFF: If you understood that they were suffering if we non-A, non-B hepatitis, or for that matter, one of those very few who suffered from hepatitis B still, there is no reference to a liver specialist in the boxes in the middle. Where would they go?

A. If there was a liver -- I would have to refer them. They didn't come to the clinic.

SIR BRIAN LANGSTAFF: So this would not be a clinic that

was comprehensive in the sense of including those specialties, apart from saying your only knowledge which you picked up -- of AIDS -- from the most practical way of all, of dealing with it.

A. If you said that a liver specialist should be included in there then, yes, it's not comprehensive then. But how can we have a liver specialist, where would the resources come from? All these people have given their own time.

SIR BRIAN LANGSTAFF: The reason I ask is that in some other centres we have had evidence that there were joint clinics arranged. So did you ever arrange a joint clinic of that sort in Bradford?

A. No. As I stated, we had to make do with the staff. There were no extra resources. There were only two consultants and, you know, I took on this project. All the people gave their time from their own employment. There just wasn't enough resources or rooms in the clinic, you know, because all the rooms are occupied in out-patients, we just couldn't have fitted any more people in there, we just couldn't have done it.

SIR BRIAN LANGSTAFF: The next question is this: you started as a consultant and then acting director and then director of the haemophilia centre in 1982 in

Bradford. Do you have any reason to think that any of your patients at that time in 1982 were then suffering from the effects of HIV infection?

A. In 1982, I didn't think there were any patients with HIV, although not haemophiliacs. On the ward, I had a young gentleman who was gay, had pneumonia, but he might have had AIDS but we didn't -- I did not have the knowledge or specialism to take it further than that because even the blood test may not have been available then -- not with haemophilia. But I didn't think anybody -- any one of my patients had AIDS, rather than HIV. AIDS is different.

SIR BRIAN LANGSTAFF: The gay man would have had signs that you recognised at the time might be AIDS but you didn't know, I see.

A. He disappeared and I couldn't trace him. But having said that, the first death with AIDS in Bradford was in a haemophiliac and that might have been in 1985, I think -- '84/'85. Sorry, '85. I think it's in the records. It's '85 and it's interesting because I gave him high dose immunoglobulins and he responded very well and we wrote a letter and he had seen a list of my publications, and he responded very well to that. My last sentence on that was that immunoglobulins should be tried in viral infections, and it's

interesting because it's gone round in a circle.

Mr Trump had immunoglobulins, didn't he, so -- and I don't know why they don't try high-dose immunoglobulins, because that's quite pooled, you know. They are going for specific immunoglobulins but it sort of came out in a circle, but that was the last sentence I wrote. It was printed in the BMJ that it should be tried.

I think the other interesting thing, by the way, I'm surprised you haven't asked me, which is still in this healthcare management, was we were the first in the world to use Monoclate, which was -- that patient is still alive, has a family, he is not positive for hepatitis and he doesn't have HIV. It was a different way of making Factor VIII, it was using antibodies which bound Factor VIII in von Willebrand, and then you added calcium chloride. You let everything else go through, all the impurities then you added calcium chloride and got Factor VIII. It was such a small amount and so soluble that they had to mix it with albumin because it was so small, to make it enough volume to be able to inject. But that was taken off the market, but Monoclate went on for a long time. But that patient never got hepatitis or HIV, which was a great success, which was a great thing.

SIR BRIAN LANGSTAFF: Thank you. Roughly, how many patients do you think you had going through between 1982, in the usual sort of number 1982 through to say, 1986?

A. Going through?

SIR BRIAN LANGSTAFF: Those four years, 1982 to 1986.

A. How many patients -- sorry, I missed the question?

SIR BRIAN LANGSTAFF: Roughly how many patients with haemophilia did you treat in the years 1982 to 1986, roughly?

A. Well, first the returns, I think, started about 18 patients but they were gradually increasing because we were getting patients from outside Bradford, as far as Huddersfield and Halifax. I think in that period severe haemophiliacs that we treated might have gone to 26, something like that, 26/28 something like that.

SIR BRIAN LANGSTAFF: Roughly how many of the 26 or so tested HIV positive?

A. I cannot remember the figure.

SIR BRIAN LANGSTAFF: What sort of percentage?

A. I don't think there were that many, actually, but Adrian Minford mentioned four. I don't know, maybe another six, seven, eight, something like that possibly.

SIR BRIAN LANGSTAFF: Per cent or number?

A. Number. There weren't that --

SIR BRIAN LANGSTAFF: So that would be about 30 per cent?

A. I honestly couldn't -- I can't remember, I can't tell you, I'm sorry.

SIR BRIAN LANGSTAFF: Why do you think, from patients who began in 1982, and you have no reason to think that they had any infection with HIV, through to, say, 1986 when tests were regularly freely available, why do you think it was that about a third began to have infections with HIV?

A. I honestly don't know but we were using commercial Factor VIII, we were using a lot of NHS Factor VIII, the usage is going up all the time. I don't know exact numbers how many were actually infected but they probably got infected with those materials, you know. There was one particular -- I think it's in the material I've given you, where a patient with von Willebrand got infected with just one batch of Factor VIII and I informed promptly and all the batches were withdrawn, and subsequently they started withdrawing the batches from two or three other hospitals very quickly. The message there was that if you used the same material on the same patient, in this one there was a change and that helped to withdraw all the rest, but they got infected like all

other patients and I think it was we found out too late, didn't we, really?

SIR BRIAN LANGSTAFF: You must have asked yourself: here am I responsible for the treatment, which they are giving, they are having, about a third end up with infection from the treatment, one way or the other, how did it happen?

A. Well, I know how it happened and I feel very guilty about it. It's the fact that I changed practice when I got appointed, I started getting commercial Factor VIII in, started using more concentrate, even NHS, and without knowing it, I'm responsible for infecting them but without any knowledge, you know, like so many directors, the best intentions -- you know this happened and all I can say is I'm sorry.

SIR BRIAN LANGSTAFF: So it was the product that you were given to use that was, as you saw it, causing the problem.

A. Yes, unknowingly, obviously.

SIR BRIAN LANGSTAFF: When people were infected, did you check back the batch numbers to see whether they probably had it from batches of concentrate?

A. As far as -- well, as we knew the batches were infected, they were withdrawn, they were brought back, they were given back. This information as it came

through, whether it came through Blood Transfusion Service or pharmaceutical companies or wherever, it was actioned immediately.

So yes, they were withdrawn. We didn't continue using them. We knew all the batches. It was all recorded. We had all the records in our blood bank, but we moved on with the products as well because this is where knowledge came and said, okay heat treatment is better than unheat treatment, heating at, was it 60 or 80 degrees, is better than 40 degrees, but the treatment is better -- and so we kept on withdrawing the previous products that had been used up and getting newer products, and then when then we used the Monoclate, which produced very good results. But that was withdrawn as well, for some reason. I don't know.

SIR BRIAN LANGSTAFF: You have mentioned a number of occasions that you were desperate for information during the time, '82, '83, '84.

A. Reliable information.

SIR BRIAN LANGSTAFF: Reliable information. To what extent do you think the lack of information may have contributed to what happened?

A. I think it may not be about lack of information. It's about delayed information. As we found out that -- the Americans had a lot of information. There was

a lot of actions being taken there. The problem was bigger. But somehow there was reluctance in Britain to accept that.

I think that that delay might have cost lives. I think the delay in the Government recognising how good the -- how good British donors are, how good is the NHS stuff, not investing money.

I mean, I've often thought about it. If it was a commercial world, if they were now in the stock market and you had BPL, what they would say is: Invest in them, you've got a free supply of donors, free plasma. Invest in them because our costs will be lower and our profits will be higher.

And those profits could have been ploughed back into getting new manufacturing plants, et cetera, et cetera. The pricing should have been in competition with commercial factor. There should be an element built in for research and development.

But what would we have? They are part of NHS, a monopoly. Government doesn't want to invest, not enough anyway. They cannot go to the City for money or investment. They cannot ask NHS staff to invest. And so I think the future was sealed, you know. It was a -- when the reps came, you could see they didn't have enough -- enough of anything, really. There were

only two reps, I think, for the whole of England, while the commercial companies had a lot more material, you know, a lot more muscle. So I think their fate was sealed actually, that they would not succeed as a non-commercial concern within the NHS.

But if they had that independence, if the Government said, "We're going to float you out", people would have invested crazily, because here was good, solid supply of good material, you know.

SIR BRIAN LANGSTAFF: I suppose another way of putting the same point would be that it would be cheaper to have invested and developed the BPL Elstree product than it would to buy the commercial product, allowing for all the profit and the uses to which the profit was put, such as marketing and commercial return?

A. A lot cheaper. The commercial companies were making -- it was an absolute fortune. The profits were incredible through Factor VIII. Which I'm sure you are aware of, you know. You are talking millions and millions, and you are talking worldwide.

If Elstree had produced, they had invested and made products, and if they were allowed to -- had been able to sell, a lot of the world would have bought it, because it was good British product, with good British donors, clean. But British donors, they give their

blood -- if there was hepatitis, they soon trace it. If somebody got it. They're withdrawn. That donor is gone. You know, well tested.

You don't need a blood test because you have been tested by giving 50 units, 30 units or -- I mean, it's a great thing that the Great British have, is their charitable generosity that they have with the blood transfusion, the National Blood Transfusion Service.

But I think it was what I called a missed opportune -- you know, I invest a lot in shares and things and, you know, I -- and I just felt that the BPL were not commercially minded, they didn't have proper backing, they were not supported, and all because they were in a sort of nationalised industry.

SIR BRIAN LANGSTAFF: Yes, I see.

Turning to a new subject, you spoke quite a bit about the way in which, as a haemophilia centre, you would operate as a family in many ways, or a friend, because you saw your patients so often, those who were severe haemophiliacs, who attended the clinics regularly. So you would get to know what they were thinking or what they picked up, and presumably, I think this is what you said, that whatever was in the press or in the media they might reflect back to

you by asking you questions about it, and you say they knew quite a bit about their condition.

A. They do. And I also support them because some wrote very -- articles that I had supported them to write, in Sunday Times and -- I've always backed their cause. I think as a society we have failed them.

SIR BRIAN LANGSTAFF: They came to you presumably because -- it must have been because -- you were the expert in haemophilia.

A. I had to learn on the job a lot. As I said, my training wasn't particularly great. I think that's something that -- I don't know whether the Inquiry is looking at -- is such a responsible post, would you have people appointed by accidental training? Surely UKHCDO should have given guidance about how people should be trained and accredited and so on. And it was really in that there were just few centres that produced the directors for themselves, for their own centres, et cetera.

SIR BRIAN LANGSTAFF: Let me change the question then.

You were in a position which they would naturally look up to as being the source of definitive advice.

A. Yes, they were actually. And I had to be honest with them. But as you said, in the conditions, inherited

blood conditions, and conditions like haemophilia, you do become -- and leukaemia, by the way, they were very close to me.

SIR BRIAN LANGSTAFF: So you said you took your lead from information because you didn't have a lot of it from the UKHCDO --

A. And elsewhere.

SIR BRIAN LANGSTAFF: And so you can't remember, I think, any specific conversation, but if somebody suffering from severe haemophilia had come to talk to you raising media concern in May 1983 or June 1983, do you think you would have told them, as being the person they were looking to for definitive advice, what the HCDO were saying, or do you think you might have said something different?

A. I think that's a bit too specific because -- I think what they would use a Director for is to get information from several sources, try and summarise it, and bring it to a language that we could converse in. You know, that we could actually talk. So we were like a filter, you know, a filter for all the information we got from various sources. But my patients were my friends.

SIR BRIAN LANGSTAFF: So what do you think you might have said -- if you can't remember, please don't try and

remember -- to someone who came and raised -- in, say, May 1983, said, "Right, I've been reading the Mail on Sunday and I've seen this thing about a killer disease, AIDS, from which haemophiliacs are at risk, am I really at risk here? Am I going to get AIDS?" What would you have said?

If you can't remember, please say?

A. Oh no, I think we're all used to the headlines that come from Daily Mail and so on. It's -- like I said, I think one has to play it down or play up, depending what's said in the papers, but they are -- what they are looking for is interpretation by somebody who has empathy for them, who understands.

I think it really depends what information Daily Mail had, because I think sometimes the newspapers have done a grand job. I think they've done a grand job trying to highlight haemophilia and the plight, you know. But sometimes it's the other way round, they cause problems, you know.

I'm sorry, I might not be answering your question.

SIR BRIAN LANGSTAFF: You aren't, but you've given an answer of a sort.

A. Maybe I can't answer it. I don't know.

SIR BRIAN LANGSTAFF: I think perhaps you can't remember

specifically, so I shall forgive you for that, if I may.

The only other matter which I want to raise with you is -- if we can have UKHCDO0000270_004, what I want to ask you about was this: this is the Reference Centre Directors sending out a report. It's recommendations which counsel took you to. It refers to a meeting of the Reference Centre Directors on May 13, 1983. As far as you can recollect, was this a time when there was quite a lot of concern about the risk of AIDS, the problem of AIDS?

A. Sorry, can you repeat that?

SIR BRIAN LANGSTAFF: Yes. Was this a time, 1983, around the middle of the year, that there was a lot of concern in the popular press, amongst those who were your friends who came to speak to you in the haemophilia clinics and so on, about the possibility or the risk of AIDS?

A. 1983 ...

SIR BRIAN LANGSTAFF: If we just have a look at the heading, Henry, it may give a clue, I think.

This is a long-ish letter all about it.

A. I think 1983 -- I mean, it's difficult --

SIR BRIAN LANGSTAFF: To think back?

A. No, I think there was -- obviously things were

happening in America.
SIR BRIAN LANGSTAFF: Let me tell you what my question is here.
The meeting is 13 May. The letter -- if you go back and down a bit further, Henry, if we may -- sorry, up. I'm in the wrong direction. That's it.
24 June. So it's, what, six weeks in 1983 where, if the American experience was right, there may be something which is labelled an epidemic which is happening. Do you have anything to say about the slowness of this letter being written after a meeting of 13 May to which the substance of it was agreed?
A. There is slowness. I mean, you know, we have said there's -- do you mean the slowness to take into account this letter afterward?
SIR BRIAN LANGSTAFF: The delay in writing it.
A. Mmm?
SIR BRIAN LANGSTAFF: The delay in writing it.
A. I think that that's what I meant, that there has been delay. There has been delays all the time, every year.
SIR BRIAN LANGSTAFF: That's what I was going to lead on -- that's where this question was leading. There were further delays, were there, in giving out information?

A. Yes, there was delays. But we were looking for leadership, and I think in some way it would have been good for UKHCDO, whichever organisation or Government-appointed or whatever, to have collated this and taken things quicker, further, faster.
Because we did have a choice -- because in this country we did have a choice, because there was an alternative company that they could have taken corrective measures with. You know, they could have reassured the population in Britain that: yes, we have a British company, with the right backing, right research, right investment, may reduce the risk.
I do not know again if I'm answering it, but the delay I think is critical.
SIR BRIAN LANGSTAFF: Well, thank you very much.
A. I think in many ways we're talking about -- comparison would be like with Covid. The delay, for whatever reason, may actually cost lives. Delaying vaccination, delaying whatever. There are parallels.
SIR BRIAN LANGSTAFF: Thank you very much.
That's all that I ask, Ms Scott.
A. I'm sorry, I was getting a bit tired.
SIR BRIAN LANGSTAFF: You don't need to apologise. You have been there all day and you have been most helpful.

MS SCOTT: Professor Parapia, is there anything you would like to say?
A. I would, but I don't think I can.
MS SCOTT: Okay.
SIR BRIAN LANGSTAFF: If you want to I'm not stopping you.
A. No, it's ...
I think it's just sad what's happened. It shouldn't have happened. And I think we should ...
SIR BRIAN LANGSTAFF: Just take a moment, please.
A. I've lost a lot of people I knew. I'm sorry.
SIR BRIAN LANGSTAFF: You have absolutely nothing to apologise for in saying what you've just said.
Can I thank you? In your gentle way you have illuminated what life was like for a consultant and director in one of the smaller units treating those with haemophilia in the early 1980s and through to 1990, and given us quite a practical insight into how you saw things and how things might have been seen in other places, and the relationship between a smaller unit and perhaps some of the bigger players, if I can call them that, in the field. That's been really most helpful.
Thank you very much indeed for coming, despite all the current challenges, to which you have made a number of references. So our gratitude to you.

A. Thank you.
MS SCOTT: Sir, we're not sitting tomorrow. I think we are back on Monday with evidence being given remotely by Professor Hay.
SIR BRIAN LANGSTAFF: Preston, I think.
MS SCOTT: Professor Preston.
SIR BRIAN LANGSTAFF: Professor Preston. That may be less than a day, I think, for those who are coming but spread over two days, possibly, as I understand it.
MS SCOTT: Yes.
SIR BRIAN LANGSTAFF: Then later in the week we hear from Professor Hay, do we?
MS SCOTT: Yes.
SIR BRIAN LANGSTAFF: Until Monday then, those of you who are coming back then. In the meantime, please stay safe and I look forward to seeing you again, those of you who return next week.
(4.48 pm)
(Adjourned until Monday, 2 November at 10.00 am)

I N D E X

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F: