Thursday, 1 April 2021

(10.00 am)

SIR BRIAN LANGSTAFF: Good morning, Dr Benson. Can you hear me?

THE WITNESS: Good morning. I can indeed, yes.

SIR BRIAN LANGSTAFF: Thank you for joining us. I hope the weather in Belfast has not -- I hope it has been as good as it has been here, although I think you are at the moment in the City Hospital, are you?

THE WITNESS: Yes, that's correct.

SIR BRIAN LANGSTAFF: In a room, private room, there?

THE WITNESS: Yes, in a private room, just with the gentlemen that you provided for the IT support.

SIR BRIAN LANGSTAFF: I'm told there may be a problem with that at a later stage because of the access question but you'll be quickly remedied if it exists. If that happens we'll just have to play it by ear at the time.

It does mean that I should say now that if there is any break what you mustn't do, because you are going to give evidence, is talk to anyone about the evidence you have given or you think you may yet be asked to give, whoever they are, but you can talk about anything else you like.

Let me tell you who you are talking to. You are talking to a very large room here, which can, when

it's full, accommodate about 200 people. It isn't full. It has eight people in it, all of whom, apart from Ms Fraser Butlin, who will be asking you the questions, and myself at the moment, are wearing masks.

Mary will come and ask you to take the oath in a moment or two. The other name you may hear is Soumik, who will present any documents that we invite you to comment on in the course of questioning.

But the real audience are the 200 or thereabouts people who are watching remotely. It is to them really that you giving your evidence. This is a public inquiry. They are the public.

Without more ado, Mary, would you ask Dr Benson to take the oath.

DR GARY BENSON (sworn)

Questions by MS FRASER BUTLIN

MS FRASER BUTLIN: Thank you.

Good morning, Dr Benson. Can I check first that you can see and hear me?

A. I can indeed, yes. Thank you.

Q. I'm going to start off by asking you some questions about your CV. You qualified and completed your medical training in 1999?

A. Yes, that's correct.

Q. You then undertook various house officer jobs between 1999 and 2003, all in Northern Ireland?

A. That's correct, yes.

Q. And you then had specialist registrar training in Belfast in haematology from February 2003?

A. Right, yes.

Q. It's right, isn't it, that you spent some time at the Royal Infirmary in Edinburgh from February 2007 through to January 2008?

A. Yes, that's correct, and as part of -- oh, sorry.

Q. No, go ahead.

A. As part of my interest or training throughout the initial part of the specialist registrar trainings in -- at the time of my declaration of interest within the area of coagulation disorders there was no full-time substantive consultant in the Northern Ireland Haemophilia Comprehensive Care Centre, so the training programme service and the training programme director then had contacts with the Royal Infirmary, largely through Dr Anderson, who had been a consultant at one of the times as my registrar timing at the haemophilia service. So it was set up through the Trust, with support financially, and through NIMDTA, and the training programme, that I would spend my final year in the programme, but with specific

training with regard to the coagulation disorders which Belfast could not have provided me at that time.

Q. I want to come back to your time in Edinburgh in just a moment, once we've sketched out your CV.

You returned from Edinburgh in February 2008 to take up your consultant post in Belfast?

A. *(Nodded).*

Q. That post includes the role of director of the Northern Ireland Haemophilia Comprehensive Care Centre, that's right?

A. Yes, the post itself is a consultant haematologist with a special interest in the disorders of coagulation, and one of the roles of that overarching post is to be the Haemophilia Service Centre Director.

Q. You are also the clinical director of Blood Services within the Belfast Health and Social Care Trust?

A. Yes, that was a recent appointment three years ago that I took up that additional role for the Blood Sciences and laboratory in clinical haematology.

Q. When you became director of the Belfast centre, you also became a member of the UKHCDO Advisory Committee; is that correct?

A. Yes, that's correct to represent Northern Ireland on the group.

Q. Now before we discuss Belfast, I want to ask about two

areas. Firstly, can you recall what you learnt during your medical training about the risk of viral infection via blood and blood products, particularly in relation to HIV and hepatitis C?

A. So even before my medical training, being a child of the early 1980s, very much aware of blood transfusion and viral transmission risks. As an undergraduate, through training for both microbiology and virology, it was very clearly taught with regards to the HIV virus and the hepatitis viruses and the risks of blood transmission. And again, that was further augmented through my haematology specialty training, and I was very fortunate, through the training, to spend a three-month allocation within the Northern Ireland Blood Transfusion Service, where quite a significant time is spent on understanding microbiological and virological screening of donated blood.

Q. Can you recall what you were taught about the seriousness of hepatitis C as a disease?

A. It was clearly taught with regards to its blood transmission route as well as, although a little bit rarely, with regard to sexual transmission. The derangement of the liver function tests in the acute stage and the acute hepatitis that is witnessed. And

then also the protracted and prodromal phase of -- for the majority of patients in an asymptomatic carrier state, with an increased risk of liver cirrhosis and liver cancer development, and also, on occasions, liver transplantation as a means of its treatment.

Q. Secondly, I want to ask you a little bit about your time as a specialist registrar in Edinburgh. During that time you've mentioned that it was arranged through Dr Anderson but did you also work under Professor Ludlam?

A. So it wasn't arranged by Dr Anderson. Because of the contact -- Dr Anderson obviously came to Belfast from Edinburgh, so based on her history with the service, the decision with Professor McMullin, who was the training programme director, and Professor Ludlam, and the Edinburgh training deanery, the transfer was done, so I was a supernumerary registrar, so that's to say I was not taking part in the Edinburgh training scheme, and I was an addition to the medical team, with the limitation in my role with regard to the haemophilia service and the management and the follow-up of the patients and surgery, and gaining experience both clinically as well as laboratory with regards to the service.

Q. Did you work under Professor Ludlam during that time?

A. I did, yes. Professor Ludlam was one of the three consultants at that time.

Q. Can you tell us anything about the approach that Professor Ludlam took towards running the department. Was it collaborative or was it a more traditional hierarchical approach that he took?

A. Never really thought about it. I think with regards to -- much more of a -- there were aspects of collaborative working, there were aspects of being a senior clinician with regards to working with a junior team and directing and supporting them with regards to it. So I think that at different times, depending on the different clinics or the needs of the service, the -- his role was somewhat different. I found him personally very supportive with regards to my interest within the specialty and certainly that he furthered that and very kindly facilitated that with his colleagues and his laboratory team.

Q. We've heard, over the course of the Inquiry, a lot of evidence from different clinicians and from patients about the different approaches that doctors can take, that they can be more of the traditional approach or they can have a more -- a different approach in relation to how they relate to patients as well. Did you observe anything in relation to how

Professor Ludlam generally interacted with patients? Was he of the more old school consultant or the more -- that's very stereotypical, but of the more traditional approach or more modern approach or more collaborative with patients?

A. I wouldn't have originally seen patients with Professor Ludlam so I wouldn't really have an observation with regards to his ways in that way.

Q. Were you aware of any research being carried out in Edinburgh involving patients?

A. No.

Q. Now, if we look at your arrival in Belfast, when you took up your post can you describe for us the physical facilities that the centre had at that time?

A. So in -- I was a trainee from 2003 to 2007, before I left, so certainly very aware of what was there at that time. As a consultant it had not changed that much from the original service that had set up further to the amalgamation of the two haematology services between the Royal Victoria Hospital and the Belfast City Hospital, and that was just before I started as a senior house officer in haematology.

So in 2008 the haemophilia centre was established and placed in the Bridgewater Suite, which is on C floor of the Belfast City Hospital, and that's

a shared floor with clinical haematology and also the out-patient cancer services. So it's a dedicated space.

It consists of, and still does today, an office which is both my office as well as a room within which I will consult with patients on a day-to-day basis. There is a treatment room which has a bed in it, so if patients were to attend during the day with a crisis or if they were going for a procedure in the hospital, they would be facilitated there and we would attend to their needs with clotting factor. If they needed to be admitted they would be admitted from that bed to somewhere else in the hospital.

Adjacent to that, there is a specialty doctor room, which our predecessor, Dr Orla McNulty, and now Dr Charlene Neill, are based in, and they're based in that room the whole time, again, their office, as well as their consulting room. As a sort of sweep-around, there's a disabled access toilet, next is a specialty registrar room, so we are very fortunate with the training scheme that a registrar is afforded to the haemophilia service all --

(Connection lost)

Q. I think we've lost connection.

A. -- majority will do too.

SIR BRIAN LANGSTAFF: We may just have lost a little bit of the sound there. Do you want to repeat where you were?

We got as far as you were very fortunate with the training scheme, a registrar was afforded to the haemophilia service, and then we lost you.

A. Okay, sorry.

So the registrars rotate on a three-monthly basis throughout their five-year training, and most of them will spend at least one three-month period but the majority will spend two three-month periods. So it is a dedicated room that they can stay in and they get their office and consulting room.

There's a phlebotomy room, where the patients are attended to separately, and attended to by the haemophilia nurse specialist with regards to their bloods, as they would need to do. We have a full nursing waiting room for the nurses. There's a waiting area within the centre and a large sort of administrative room, which will take the data manager, the haemophilia service secretary as well as a receptionist. So we have a self-contained unit within a unit. And all medical records pertaining to the haemophilia or all of the patients that are looked after at the Centre, not just haemophilia, their

medical records are retained within the administration room separately.

MS FRASER BUTLIN: We'll come back to medical records a little later this morning. What I want to pick up now with you is some sense of the staffing that's been in place at the centre. And if we start off with when you took up post, I understand from your statement that you were a single-handed consultant with Dr Orla McNulty as the specialist doctor.

A. That's correct. And Orla was regraded as an associate specialist during my time there prior to her retirement. Then there were two full-time clinical nurse specialists, with Sister Colette McAfee and Staff Nurse Margaret O'Donnell. So with regard to the medical and the nursing makeup of the service in February 2008, it was a total of four staff. We had a secretary and receptionist and two biomedical scientists within our laboratory undertaking the specialty coagulation investigations both for the patients but also for the region, in Northern Ireland, and a clinical scientist, Dr Paul Winter, responsible for the genetic screening of the patients.

Q. So that we can get more of a snapshot of how things were when you arrived, could we have a look at the 2006 UKHCDO audit.

Soumik, it's WITN3082025.

We can see on the first page, towards the bottom, that although it says at the top it's a 2006 audit, we can see that the audit visit was actually November 2007 and the final report was submitted in September 2008.

If we then turn on to page 13, internal page 13 -- this is something I'm going to pick up later but while we're in the document we'll note it -- it says that the previous audit in 2003 -- ah, sir, we've completely lost Dr Benson.

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: I wonder if we take a moment's break.

SIR BRIAN LANGSTAFF: We'll just take a moment to see if we get it back.

I am told there was a test conducted yesterday morning, which was fine, but we were warned that there might be -- because it's a Wi-fi system that serves quite a number of appliances, there might be an outage. We'll take a break.

MS FRASER BUTLIN: Thank you.

(10.17 am)

(A short break)

(10.20 am)

SIR BRIAN LANGSTAFF: So we have to pick up again from --

you were talking about the previous audit in 2003 from the document on the screen.

MS FRASER BUTLIN: Thank you, sir.

We were looking at WITN3082025, page 13.

Dr Benson, we'll come to this later. I just want to note it while we're in this document. The 2006 audit recorded:

"The previous audit in 2003 that highlighted the need for hepatology services -- this has now been addressed."

As I say, we'll come back to that. But if we can carry on to page 17 in this document, under the heading of Comments, it noted that:

"There have been no meetings with Trust management at BCH for more than 2 years. This must be addressed given other issues that are highlighted in this audit report. Communication between Trust, clinicians and commissioners appears to be very poor."

Is that something you were aware of before you arrived?

A. It's not something that I would have been aware of before I arrived but it's certainly been something that is not the case from 2008 onwards. There are regular meetings between myself and the specialty commissioners at the Health Board with regards to the

haemophilia service budget and staffing, and also regular meetings within the haematology directorate and management structure. So I can't speak of them but I certainly know from 2008 the lengths which we had gone to in order to engage with all the management and the commissioning group.

Q. In terms of the staffing, if we turn on to page 24 of the report, under the heading "General comments", there's a note that the lack of permanent centre director has had an impact on all members of the multidisciplinary team and it goes on to describe morale as being at an all time low. Again, is that what you found when you arrived, that morale within the staff team was very low?

A. I think with the arrival there was great positivity and there was a lot of really looking forward to working together and moving forward. During my time in Edinburgh towards the end of it, having been interviewed and successful for the post one of the things that I had done whilst there was to really try to review the service as it had been within Belfast and to try to focus attentions by developing specialty clinics, so for example a general review clinic would have had patients with all of the disorders of coagulation, both bleeding and clotting, coming up to

the same one. So with an aim and a goal to develop a multi-professional team it would be difficult to think that they would be on standby for every clinic.

So one of the earlier things that were put in place before I started was to construct a dedicated haemophilia home leave clinic on Friday. This just allowed the men with haemophilia to come up and it was a bespoke clinic. This allowed myself and staff to focus only on haemophilia-related needs, it allowed the laboratory to focus on the samples only coming from the men on that day. In addition to focusing on that, we also -- I was also in communication with the obstetrician -- one of the services of Edinburgh that I thought worked exceptionally well was a combined on-site obstetric high-risk clinic which Dr Horn had undertaken on a Friday morning. So I had been in touch with Dr Harper, who had been the specialist with regards to bleeding disorders and really offered, as I constructed a job plan and a job timetable for myself, to seek to put in a high-risk haematology obstetric clinic, which Dr Harper and subsequently Dr Hunter were both exceptionally positive towards.

That's been running -- it started six weeks after I had started in 2008 and continues to run on a fortnightly basis for women with bleeding disorders

who are pregnant and going through pregnancy, as a regional service.

So with regards the development of that, leading up to my post, I required the team to assist me and to listen to ideas or to concepts. The kind of thing that they really were very helpful to me for was the construction of a questionnaire that I had written to the patients themselves. The overriding focus that I have always had has been that the haemophilia service should be there to meet the needs of the patients themselves. We're not there to meet our own needs or what we think that they need, it's for us to understand from them.

So I'd done a questionnaire in Edinburgh and provided a stamped addressed envelope and that was given out by the team in Belfast prior to my appointment and the results of the questionnaire, all anonymous, were forwarded to me in Edinburgh for reading. That was really quite telling from the patients' perspective as to their observations of care and how things had been. But in response to how to improve things or with regards to their needs, they really constructed the last ten years of my professional service in going through that and aiming to achieve it. I couldn't have done that without the

team and their motivation. It could be considered that having been so low for so long, as the audit would have suggested, that that would have continued, but I met an exceptionally excited and motivated team who I think, as the audit alludes to, were delighted to have a new consultant centre director and colleague to work with them and really to highlight the good work that had been done by them and sometimes just to acknowledge that.

The other bit with regards to multi-professional team working was on a Monday morning, as they had in Edinburgh at that time, was to invite all members of the team in the laboratory, the administrative staff and clinical scientists, medical, nursing, on a Monday morning, together in our multi-source room and we would discuss all the patients that would come up that week so that we were all made aware of the new patients and tests or the reviews of patients or to highlight patients that had perhaps phoned the out-of-hours over the weekend or who were in-patients.

That led itself then on to a CPD session on a Thursday morning for all of the team to come together and to learn from each other, initially at the start, mutual respect for actually what

everybody's job was.

So, you know, there's a lot of planning during my time in Edinburgh further to the successful appointment and a lot of excitement and support for the team that were there.

Q. You have spoken just now about the patient survey you undertook before arriving. Can you tell us what the key issues were that were raised with you by patients?

A. Yes. I think that for some of them engagement long-term had been challenging. I think that with regards to emergency management or complications or challenges that they would have used the service and been very happy with the service, but I think that long-term goals, I think, weren't necessarily being followed through. Some would have reflected what the point of going to the clinic was because, from their perspective, they knew their haemophilia, they knew the treatment and we provided the factor, and perhaps the lack of understanding of what long-term review would be.

Home delivery was one. So up until, actually, autumn last year Northern Ireland did not partake in home delivery of clotting factor concentrate. Patients would phone the haemophilia centre and their factor would be provided to them through their local

hospital's blood bank for their convenience. So home delivery was an important one.

A lot of them had reflected, based on the quite recent second ride out with regards to variant CJD, and a lot had shared their feelings on that subject with regard to their upset and anger.

Q. We'll come back to that a little later on. We were looking at the audit report and before we leave that document, if we can look -- have it back up on the screen, Soumik, at WITN3082025. Just looking on page 25, and we can see, in the last two paragraphs, in relation to staffing:

"Although the nurses describe the present establishment as 'adequate', it is noted that there is not a designated social worker or psychologist at this Centre and this tends to increase demands on the nursing team ..."

And:

"The lack of direction for the Centre as a whole is reflected in lack of development of nursing roles and in other roles within the multi-disciplinary team. The model of care in the Centre has been mainly 'Medical' and with support, from the Centre Director and Nurse Managers the Haemophilia Nurse Specialist has the expertise ... to expand her role ..."

Just in relation to the reference of the model of care being mainly medical, what was meant by that, what did you understand to be being addressed there?

A. Probably initially in reading it, it may be the authors of the report may have a better understanding of what they were meaning really by describing the centre like that. From my perspective, I'm not entirely sure what they may well have meant. I can have some conjecture with the meaning of it.

I certainly think that, from my appointment, the multidisciplinary team had been grown and has been developed and the roles have been grown with that for everybody involved to complement the needs of patients but --

Q. One reading of it might be that the care is very consultant centric with others providing support but that the previous consultant or the senior doctor at the centre really was the central point of how care was provided. Would you that be something that the staff would have recognised before your arrival in the centre, that it was a very consultant-centric approach?

A. Before my arrival there was no consultant.

Q. But historically?

A. Well, from Dr Anderson's retirement and leaving the

centre to my appointment over the four years with the services managed by an acting consultant, with regards to the oversight of it, I'm not sure what their medical input or reviewing of patients was going to be. So, with regards to senior medical, I don't know what that role would be.

Q. When you arrived, did the staff ever reflect with you of how the centre had been run historically, perhaps in Dr Mayne's time, of how the centre was structured and run?

A. Not particularly. I think that there were some reflections with regards the physiotherapy service, which had been provided at a time in the Royal Victoria Hospital through Lynne Crockard and a lot of the patients had remembered her very fondly with regards to that at the time of the Royal, but that hadn't transferred across to the City Hospital site. So I think with regards to allied healthcare professionals, I think that that's probably the only one that would, sort of, certainly stand out as part of their reflections.

Q. In terms of staffing, if we then go on to the 2009 audit, it's WITN3082026. Again, we can see that the audit visit was actually in January 2010. That's at the bottom of the page.

Then if we carry on to page 22, and towards the bottom of the page, paragraph 9.3, we can see the issues that were identified during the audit meeting. First of all, the need to give consideration to establishing a second consultant post. Then if we go over the page, Soumik -- thank you -- the first two bullet points address Dr McNulty and the banding, the grading, of Nurse McAfee. If we carry on further down there are two points:

"It is recommended that social work time is clearly dedicated to haemophilia rather than existing arrangements of cover ..."

The next bullet point addressing the need for a data manager.

Was that an accurate reflection of what the key needs of the service at that time were?

A. Yes, I think looking at the Haemophilia Alliance through the service specification, if we were to call it that, with regards to Haemophilia Comprehensive Care Centre, they are often volunteered as key members of staff. With regards to a factor allocation and tracking patients and the volume that they got and their follow-up, that was something that my secretary had done and I had continued that with regards to spreadsheets and that was used, really very helpfully,

to inform commissioning with regards to the use of factor and where it was going and what it was being used for.

I think with regards -- so I think a lot of the roles were being done and were being done as part of the medical and the nursing staff's role. Since that, as we are aware, data manager funding had been provided and had been recruited to a dedicated social worker, rather than just access to the haematology social worker, which was invaluable service whenever it was called on, that we have a dedicated social worker for haemophilia, both adults and children, and that post was agreed.

We did have funding and a post holder for the second coagulation consultant, as and when an interested person was able to declare that. Dr Chris McCauley came into post and after two and a half years he resigned and has moved on to another haematology service. His post has been readvertised and we had two applicants, both of a very high calibre, and that was supported by the Trust and the Specialty Commissioning Group to appoint both candidates.

So, over the next few months, the consultant workload in the Northern Ireland Haemophilia Centre

for the first time ever will be three whole-time equivalent dedicated consultants. With regards to the out-of-hours cover that Dr Wilde was reflecting on in the audit a lot of that would have fallen to myself, that whilst my clinical colleagues who covered the leukaemia bone marrow transplant team would have also managed the in-patients for haemophilia, I was very happy and content to be second on call, but if there were any specific issues that ever arose and they wished to speak with me, that I was happy to do and they did.

Q. So, in terms of the staffing position now, you've noted the data manager, the social worker and two further consultants who will be joining soon. In terms of the nursing staff, what's the position with that now?

A. We have four nurses. So we have Sister Helen Manson, as senior clinical nurse specialist, Kirsty McMurray, we have Jackie, and we also have Christine. So we have four haemophilia nurse specialists working along with us. We have a dedicated haemophilia physiotherapist and we also have funding for a haemophilia physiotherapy assistant, as well as -- and we also have full-time haemophilia dedicated occupational therapist.

We got additional funding with regards to a second clinical scientist, to work alongside the then single post holder, and we are currently seeking support in line with the new coagulation factors to support our laboratory staff with an additional two biomedical scientists to go in.

Q. In your statement, you say that you previously could refer patients to the Psychology Department if there was a need for increased therapeutic support but, until recently, that wasn't a dedicated service; is that right?

A. No, exactly. So as with regards to any patient in any hospital there was open access with regards to the Adult Psychology Service. So with regards to specific trained counselling within psychology, that was there and patients were referred on. The counselling also took place informally by the medical nursing team, with regards to talking to patients. We're not just there to ask them about their bleeds and how much factor they have taken since the last time they were there, but really to reflect with them during the period of time between their two hospital visits how things were going for them, both in life and relationships, and with regards to work, and it's one of the bits of the post that I -- I use the word

"love", I think it may be a little bit strong, but just sitting down and just having a chat with people and just seeing how they're going and how can we help them in any particular way, and because of those chats then that's where the whole team has come out of because from that then how can we best meet those specific needs?

So I think counselling is not just as a role for specially-trained people but I think it's just giving people time and not being rushed at clinics. So we lengthened hospital appointments with regards to outpatients to make sure that it was more than that. So part of that feedback of patients through that original questionnaire that I have done was really just that they weren't quite sure, you know, the purpose of coming up, or anything like that.

So I think building that in has certainly helped engaging with our population. The do-not-attend rate at the clinic has been reduced by altering the model and how we deliver our care.

Q. But, in terms of formal therapeutic intervention with a trained psychologist, that wasn't embedded as part of the multidisciplinary team until very recently?

A. Yes. So, with regards to just before the advent of the Inquiry, whenever we were aware of it, I had

advocated on several occasions with regards to that. Part of the social worker appointment, again, was being very minded towards psychosocial training that they would have already had in place and that we were able to avail of that background specialty training that they already had too.

We now have an appointed whole-time equivalent clinical psychologist for the service and the Trust had gone out to make that a permanent post, rather than just -- rather than a temporary one for the duration of the Inquiry.

Q. Just before we look at that, can you help us with this: between your arrival in 2008 and this dedicated service that's been established more recently, I think you just said that you had sought a more dedicated psychology service, in addition to your social work provisions; is that right?

A. Yes. At all times with regards to the outcome, when it comes from any of the audits, they are shared with the Trust and they are shared with specialty commissioners with regards to outcomes and what can be achieved and what may be realistic or how we can go. So it's been very clear with regards to the need for that. I think that, at the time, with regards to our social worker appointment, we were very much minded of

psychology support and I interviewed over three days for our social worker, and one of the key components of that was to ensure that there was, sort of, a psychological background or psychosocial training that they had and they had experience of.

Q. Do you know why a dedicated psychologist hasn't been appointed previously?

A. No.

Q. You have just said that since the start of the Inquiry that there has been a dedicated psychology service. Can you tell us a little bit more about what that service consists of, how many days a week or month it's available?

A. I think it's quite variable. It can be something that can be undertaken depending on what patients' specific needs are. It has varied a little bit during Covid with regards to availability at weekends, as opposed to during the week, to reflect the working pattern of our psychologist. Patient Access can do so directly, either via the social worker or myself, and patients are put in direct contact with the psychologist and appointments are provided. They can be remote through Microsoft Teams or Zoom, or initially prior to the Covid pandemic they had been face-to-face.

With regards to the number of patients and the

frequency of sessions that have been provided, I'm not privy to the discussions or anything else that goes on, outwith being assured that an individual has kept the appointment that we have referred them to and that they are being followed up. So we do get informal feedback from the patients themselves whenever they attend for their haemophilia review and they do share the fact that they are attending and how they are finding that.

Q. Who can access the service? Is it only patients of the centre or can those who are affected also access the service?

A. It's designed as an open access with regards to anybody who feels during -- as an infected or affected individual. I think that in some circumstances it can be difficult for us, depending on if there are any other family members who are actually still under the care of the service, in order to ensure that we are 100 per cent able to provide that. But at any time, if a patient, or they volunteer their relative, is struggling particularly then we are able to intervene and to offer the service.

Posters are placed up in our waiting room, in our Altnagelvin clinic, which is a satellite service which we had started several years ago to meet the

needs of our patients in the north west of Northern Ireland. Again, the information is provided there and a specific leaflet has been designed and drafted by the psychologist and the Trust with regards to signposting, not just to the Trust's service in case patients feel that they don't wish to avail of that, but also through the Red Cross and through the Inquiry site itself.

Q. But if an affected person no longer has any contact with the centre, for example if their relative has sadly died, would they be able to access the psychology service or is that not possible for them?

A. Yes. No, it's a fully open-access service. There's no restriction at all. More than happy to take any contact from anybody who has been touched at all by it and there's no need that you just have to be a patient in order to access.

Q. Are you ever told about what is discussed in those psychology sessions or are the sessions very strictly confidential?

A. Well, I think it's entirely confidential. I think there's a professional code by which the team work with. There's absolutely nothing that ever gets discussed with me. We have had feedback through our continual professional development meetings and our

psychologist has presented to the rest of the team with regards to techniques or things to help to support patients, rather than simply signposting how can we deal with events or crises, as and when they arise, and they are being discussed with us, so they have been very helpful for those sorts of things but anything that does get discussed remains there.

Q. Do you have any sense of how much uptake there's been for the service?

A. I think with regards to the referrals that have gone through, I think with 90/95 per cent of patients have attended for at least one session. Our psychologist would be able to give you the more accurate figures with regard to those who have fully engaged. But I would be able to confirm I do receive a letter back to say that contact was made and that sessions and goals had been set and are underway.

Q. If we can move on to the broader questions of management within the centre, the centre is the comprehensive care centre for the whole of Northern Ireland?

A. For adults only.

Q. For adults. From your statement, it's clear that the team will also provide advice to local hospitals where that's required; is that right?

A. That's correct, yes.

Q. Could you just clarify then whether all patients with bleeding disorders are registered at the Belfast centre or whether there is some element of being registered at local hospitals as well, and how does that work?

A. So all patients are registered at the Belfast centre. So all patients from the age of 14 can transition from the paediatric service. So any time, any age from 14 to 16, based on the definition of a child at our paediatric service. So from that age they will come across and they are all registered here within Belfast. From our perspective, we do undertake a satellite clinic in Altnagelvin Hospital in the north west and we undertake that and have undertaken it, on average, alternate monthly. However, based on the current Covid pandemic, that's not been possible but we have engaged with those patients remotely using Microsoft Teams consultation but those patients remain registered in Belfast --

(Connection frozen)

SIR BRIAN LANGSTAFF: We're stuck again, I'm afraid.

MS FRASER BUTLIN: We're stuck again.

A. -- myself will travel up there to see patients.

SIR BRIAN LANGSTAFF: We just lost you for a moment or

two. You were telling us of Altnagelvin and the arrangements now happening. The last words we have are:

"... those patients remotely using Microsoft Teams consultation but those patients remain registered in Belfast ..."

Then we had a freeze on the transmission.

A. Okay.

SIR BRIAN LANGSTAFF: So if you can pick us up from that point.

A. So, during non-Covid time, whenever the clinic happened our entire team travelled up together. So myself, the nurse occupational therapist, physiotherapist and social worker would attend to the patients locally within their own hospital but they were not registered there. So we would avail of the services, take their blood, do our assessments, have their medical records with us, and then they would return back to Belfast.

MS FRASER BUTLIN: You have mentioned there the transition from paediatric to adult care takes place from between 14 and 16 years old. Why is that? Why is it 14 to 16?

A. Again, there may be a lot of questions with regards to Northern Ireland's ways that will have a lot of why

and I will perhaps struggle to explain it, but our paediatric hospital and its Accident and Emergency Department does not take children beyond their 13th birthday. So in emergencies then those would be transferred over to the adult Emergency Department. So working along with the paediatric team, generally we are content to transition from the age of 14. Most will have come aged 15/16 and transfer across.

Q. Can you tell us a little bit about how you organise the transition of care between the paediatric team and your team.

A. So it's a very fluid sort of shared-care type basis. It's sort of reflected more in the current West Midlands quality review of the service, where transition was specifically reviewed, and the team had worked quite extensively on that. I think some of the UK may use the system Ready Steady Go to try to prepare the young man and also prepare parents. Sometimes it can be as distressing to the parent leaving the paediatric service as it is to the child. So it's preparing them, setting their goals, what do they want to see or achieve, and then to come across and then to understand how services are slightly different.

A lot of the young men and young women find it

a little bit more unusual that they are being spoken to rather than their parents, so they are usually doing their best to try to get me to look at their Mum or Dad in the room, rather than having a chat with them.

So that would be an open thing with regards to their birthdays. We don't have a set time of the year where we would do that officially. In the past couple of years, whenever Dr McCauley was working alongside ourselves and team, we would have supported Dr McCartney at that time whenever she was a single-handed paediatric haematologist, and that was certainly very rewarding from our perspective and our team to be able to at least meet the children at a younger stage so they can become familiar and the parents become familiar. But as I've gone on through the service, now almost 13 years as the consultant in charge, it's the rewarding nature of seeing the mums who are carriers and their sons who have been born with haemophilia in the paediatric service and watching them come across to ourselves.

Q. In terms of out-of-hours care, what was the position when you first took up your post in 2008?

A. So the haematology out-of-hours service back in 2008 ran along the lines of two consultants on call. One

consultant team where specialist interest with regards to leukaemia, bone marrow transplantation, and that is where I was slotted in with regards to haemophilia. In essence, that team was really the historical Royal Victoria Hospital haematology team. That was made up with Professor McMullin and Frank Jones, both of whom had had prior experience and knowledge in managing haemophilia during their time as consultants at the Royal Victoria Hospital before they came across.

The other haematology team then would be classified as the lymphoma and myeloproliferative team. So out-of-hours, if there were any issues with regards to the haemophilia patients or patients under my care, that would have been discussed with that team on-call, with *(unclear)* and myself, and there was a potential of the 1 in 3, 1 in 4, that I would have been the consultant on-call for that weekend, we would have started at 9.00 am on a Monday and finished at 9.00 am the following Monday.

If any of the nature of anything that came up would have gone on to the consultant I would have wished for me to have a specialist input then I would have been phoned directly and happy to be so as second on call.

Q. But in terms of how the patients accessed out-of-hours

care, how did that work?
A. Sorry, apologies. That's too much. So from the patients after 5.00 there was a helpline number and the patients would phone the helpline in Belfast and that was staffed by a nurse specialist who would redirect the call and the message to the on-call haematology specialty registrar, who would have attended to the call and given advice and discussed it with the consultant. If patients required to be admitted or to be assessed that would have been targeted initially through the Belfast City Hospital Emergency Department, and that has been closed and it's now been redirected through the Royal Victoria Hospital Emergency Department.

That allowed us to have factor ordered and on standby in the Emergency Department and, where possible, the registrar would attend there. Alternatively, Altnagelvin Hospital, for those patients who are a little bit further away, equally we would have the discussion with the Emergency Department there. Emergency stock of clotting factor sits in Altnagelvin blood bank and, again, we can have that ordered and on standby and direct the emergency team with regards to the care and the throughput of patient whenever they arrive.

All helpline calls are discussed the next morning with the team and they are followed up appropriately, as too, on a Monday morning, do we follow up all of the out-of-hour contacts over the weekend.
Q. Is that the same system that's applied now?
A. Yes. The same system is applied now. The number of consultants with regards to on-call instead of two teams, it is just done as a single consultant on-call and I remain second on call for all of my colleagues, and we have a WhatsApp group, whereby it's an easier way to contact me as and when or should I be required out-of-hours throughout the weekend.
Q. In terms of routine management of patients at the centre, how's that organised? How often will you see patients?
A. So with regards to patients, we look after many bleeding disorders so if we look after and we discuss those with haemophilia A and haemophilia B first. So we do an all-day Friday clinic. It's generally concentrated to the first Friday of every month and this is largely done as a bit of a round robin, not quite speed dating but there are different stations that the patients will go around.

They will all be seen by a doctor, either

myself, the specialty doctor or the registrar. They will also be assessed and reviewed by our nursing team who will undertake their nursing needs assessment and routine blood check and screen.

Our physiotherapist is on site, our social worker is on site, as too is the occupational therapist, and should the patients need to be such, they can be addressed by any member of the allied healthcare professionals that we have available to them.
Q. How often will a patient come in for that review?
A. So with regards to the expectation of patients with severe haemophilia A or severe haemophilia B, the expectation is that they are invited on a six-monthly basis to attend the hospital for their review, and they get their joints scores done at least annually, with regards to their physiotherapy or their occupational therapy assessment.

Moderate haemophilia, a largely significant proportion of our patients with moderate haemophilia are on routine prophylaxis and as much we would view them as having the same review process of six-monthly.

Our patients with mild haemophilia we have trialled and undertaken and presented the use of a telephone virtual review service for those patients,

largely because they actually carried the largest "do not attend" rate at our outpatient service whenever I started. So what we have done was to engage with them and did a working day, provided a lunch and a discussion as to how we could improve things for them.

So initially it would have been a phone call, once a year, and then the following year they would have a face-to-face consultation. Again at the same Friday clinic, and again with the same access to all of the other services.

Our patients with von Willebrand's disease have a similar service set for the third Wednesday of the month, whereby the whole team as I previously described for haemophilia are there for those patients with von Willebrand's disease, and it would follow the same pattern.

Patients with type 3 von Willebrand's disease, which is the rarest but perhaps the one that bleeds the most significantly, within our adult population we have three patients. We would review them on a six-monthly basis. The vast majority of other patients with von Willebrand's disease we reviewed annually or, depending on their bleeding challenges they faced, up to six-monthly.

Q. In your statement you've also talked about family support days that the centre has organised over the years. Can you tell us a little bit about those?
A. Yes. So it started quite soon after I had started. The Haemophilia Society itself within Northern Ireland had not had a strong presence. So, with regards to the haemophilia centre's role, I did feel that there was a lot of feedback coming back from patients going, "Oh" -- in their own particular way, going: What about such and such, and I haven't seen them in a while and what's going on? Some of that was addressed by doing the specialty-specific clinics, so it was always nice to see some of the men bumping into boys that they would have sat beside in a paediatric ward many years ago and to see them catch up.

So we had initially been approached by the Roald Dahl Foundation for the first family day, which was amazing, and that we had written out to all patients, both adults as well as paediatric service, and invited the patients up, and the Roald Dahl Foundation had covered that day for us. And we had run a small educational discussion that I had led in one of the halls of the Folk and Transport Museum, for the parents to come, and there were various other activities, and there was a barbecue at the end of the

day for them.

It was very successful and, further to that, then we had organised two further educational days, by the centre staff themselves, one in the Ulster Museum, at a dinosaur exhibition, and a very nice dinner that night. And then more latterly, at the Titanic museum in Belfast, we had organised another educational day to facilitate the families to look at that new museum in Belfast.

Since then, latterly there have not been that many. Haemophilia NI itself has been founded by our patient group and they have organised and we have fully supported their own family days.

Q. If we can now just move on to look at some figures. You have said in your statement that in 2008 there were 292 patients with bleeding disorders registered with the Belfast Centre. 41 of those were people with haemophilia A and B and one was someone with von Willebrand's; is that right?
A. The classification of the smaller numbers will reflect the more severe bleeding phenotypes, so it's not all haemophilia A being 41, that would be the severe subtype.
Q. Soumik, could we turn up WITN3082028, which is the audit that was undertaken in October 2019.

And if we turn to page 7, there's a table in the middle of the page giving the number of patients registered at the centre: 58 with severe haemophilia A, 16 with moderate haemophilia A, 109 with mild. And then we see the figures for haemophilia B: 5 people with severe haemophilia B, two with moderate, 10 with mild, and then 100 with von Willebrand's.

In your statement, Dr Benson, you have given some slightly different figures. You've given a figure of a total of 596 people with bleeding disorders registered with the centre, which is rather more than we see in the audit and --

A. So with our current data manager we have undertaken a review with regards to changes in classifications, particularly with regards to female carriers who are themselves affected and whenever they have been entered in and -- to double-check through data cleansing. So there's a proportion of women who have -- or carriers who have a level of between 20 to 40 per cent who, by current classification, would be considered to have mild haemophilia. And equally then we have had transitional changes with regards to children in the interim between the two reports.
Q. So the figures you give in your statement, of

596 people registered with bleeding disorders, registered with 64 people with severe haemophilia A or B and three with type 3 von Willebrand's, which figures do you think are more accurate?
A. Those figures will follow from the time that the audit was done, and they were generated from the haemophilia database at that time. So the figures that I have given at the time of my statement trump the figures that were from the audit.
Q. Thank you.

If we can move on now to the products that were used and are used within the centre. When you started at the centre you say in your statement that since 2008 all patients with haemophilia A have been on recombinant Factor VIII. Is that right?
A. That's correct, yes.
Q. All but one patient with haemophilia B has been on recombinant Factor IX?
A. That's correct. That patient who had received recombinant Factor IX had not felt personally that it was achieving his bleed control that he had previously experienced with regard to his plasma-derived Factor IX, and as such he chose to return back to the plasma-derived Factor IX.
Q. Those with von Willebrand's disease receive either

DDAVP or intermediate purity plasma-derived clotting factor?

A. Yes, that was correct at the time of the statement. The current recombinant von Willebrand factor is now available within the UK market and we have that in stock now to be used within its licensing for on-demand.

Q. In terms of current arrangements of obtaining the product, I understand from your statement that all products are tendered and procured through the national clotting factor tender process?

A. That's correct.

Q. What's your role, if any, within that process?

A. The role has changed a little bit from whenever I have started to the way that the role is now. I think that at the start representation provided through Northern Ireland with regards to the tender process or the -- what was originally sort of volume-based purchasing of factor. So we were able to risk stratify -- or I was involved for Northern Ireland's behalf to risk stratify products by a weighting criteria in relation to evidence to support its particular use. So that was quite an intensive thing that was undertaken initially with regards to the procurement. And Scotland, Wales and England had

their own representatives involved in that.

More latterly then it's being undertaken as a flat per unit cost that is being managed through the central medicines unit. As a Haemophilia Centre Director, I'm kept up-to-date with regards to the discussions and also with regards to the contract and the wording of it as to how -- just to make sure that it meets needs of patients.

Q. When you are discussing with a patient the type of treatment you're going to give them, what information would you give them about the risks and benefits of the type of treatment?

A. I think over the years there have certainly been occasions whereby a recombinant product X will have to change to recombinant product Y, particularly with regards to haemophilia. The largest switch occurred a number of years ago whenever a product withdrew from the UK market, and as such we had to have that discussion with the patients.

I think what's always important is the reassurance that it's a recombinant product that we're changing from one to another and that we're not going, back to plasma-derived. So being able to provide them with that reassurance, it always gives us an option to have the discussion with them with regards to second

generation Factor VIII versus third generation Factor VIII. Also, more latterly, it gives us the discussion with regards to standard half life or enhanced half life as well as non-factor replacements. So the choice is certainly expanding and has been over the last number of years as to what patients may wish.

I think one of the greater risks are always changing and whether or not the product itself is as effective as what they have been on, and certainly a lot of the discussions with patients have often come back to ask me, "But I'm okay on what I'm doing, I'm not bleeding", and going, "But you don't need to change, we're just offering that there are alternatives", but which may involve less venapuncture or less administration that they would have to go through.

There's always a risk or theoretical risk with regards to inhibitor development, and we always try to make sure that at least that is updated. In more recent publications and reviews that risk has not been upheld with regards to it but it's always something that we have to bear in mind in changing.

The one that most -- that men want to know about is what dose do the vials come in. So I think sometimes with regards to the choice of a particular

product, they don't like having to disconnect two syringes to inject through their butterfly; so they do like having a product that comes all in one vial. So some products are offered through different concentrations that we base that with them.

So with regards to it -- at any time of changing or any change in contract, all the patients had been written out to. More so with regards to the volume-based purchasing of factor, letting them know what the outcome of the tender had been, reminding them of the product that they were on and whether or not they needed to change. So even the men that we didn't feel would require to change and there was no need with regards to the tender to change, they were informed, but equally asked whether or not they actually did want to take the opportunity to alter their product.

But we go through that on a daily basis with regards to the clinic. Whenever the men come up we review what they have been taking. We now have Haemtrack in place with regards to tracking what their usage with regards to their factor is, and then we can get a better feel of whether or not doses need to be changed or even the product or the frequency of injection can be changed.

Q. When you're dealing with -- or when you were dealing with plasma-derived clotting factor for von Willebrand's, what information did you give to patients about potential risks of pathogenic transmission?
A. So we changed a number of years ago from one product to a second product, largely because an additional viral inactivation step was introduced into a product and then it changed its branded name. So from my perspective the patients had been managed for many years on product X and they were very well versed and familiar with that. I would, however, always view any patient I meet for the first time as a new patient, and it would have been my routine practice to explain to them with regards to the product that they would get that, at that time, von Willebrand factor is derived from blood donors, it is screened for known pathogens with regards to HIV and hepatitis, and that it is not sourced from UK blood plasma.

They are also informed that -- with regards to the choice in the treatment of it, if it is the as-required, and therefore, we will have to balance with the patient with regards to any procedure or surgery that they are then going with and explain to them from -- what the proposed plan was going to be

and following them. It would have been, and had been, the routine practice for those patients receiving any plasma-derived product with regards to vaccination for hepatitis B, and a lot of time would have been spent in checking a patient's response to that vaccine, and immunity, and explaining that to them while we were doing it, because of the risks.
Q. Would you provide any written materials to patients after those sorts of conversations?
A. It wouldn't have been routine practice. I would have to say, from my perspective, until more latterly, particularly regards to the enhanced half-life products. I think that whenever we're explaining a Factor VIII molecule, albeit recombinant, and then stating that extra proteins are being added on to that Factor VIII product, it's much more important for the patients to be able to understand what those proteins were, and a lot of the time we would have provided review articles or synopsis with regards to the advantages of using such products. But certainly the insert from the product itself is delivered to all the patients and that's able to detail any of that additional information.
Q. Would those sorts of discussions also be recorded in patients' notes?

A. Yes, with regards to product switching, it would be recorded in the notes and reflected in the GP letter, the information would be shared with the blood bank to ensure that if out-of-hours the patient were to present to ensure that they're consistent with regards to the brand of the product the patient would receive, and also we would update then the patient's registration card that they carry on themselves with regards to the new product details.
Q. When you're seeing a patient today in clinic at one of those review appointments that you have spoken about, what tests are you doing on a regular basis?
A. So I think the most routine thing is the history and seeing how they are. I think that's the only way that you can actually interpret a test is to know actually how the patient is on the day. Routinely, we will check a full blood count, checking the haemoglobin, the white cells and the platelet count. Often that can be quite telling, particularly with bleed frequency. Picking up iron deficiency is not an infrequent observation with regards to our patients. We would routinely do liver function tests and kidney function tests and we would also routinely check their Factor VIII level or their Factor IX level or their von Willebrand level and, for those patients who are

on routine prophylaxis, we would match that to the time that they last took their injection. So that gives us an approximate pharmacokinetic result of the patient. So if they said it was 24 hours ago, I would have a rough idea of what level I should find and if we find that, then we are reassured with that.

For sub-specialty types of bloods, in the past for our patients who had had hepatitis C we would have routinely undertaken an alpha fetoprotein for those patients, regardless of their history with regards to their hepatitis C, and we would have undertaken that routinely.

We can undertake from time to time iron profiles for our older gentlemen patients and if they were over 50, we would routinely undertake a prostate-specific antigen and over the years we have, on average, detected about one case of a palpable prostate cancer in a man with haemophilia annually. So they would tend to be our more common routine bloods, full blood count, renal function, kidney function and their factor level.
Q. Can you describe for us the consent process that you'd undertake with a patient at a routine appointment for those tests?
A. Yes. So probably the men would come in. My routine

practice would be to go through their history, see how things have been going with them. We would pull up on the computer screen bloods and blood results and to discuss those with them and to complete the same test that we would be doing today or additional ones, depending on how they were feeling.

As I'd earlier said, on a Monday morning we have a multidisciplinary meeting with our laboratory staff, nursing staff and all of our other allied healthcare professionals and, at that time, we go through each individual patient who will be coming to the clinic. We discuss and reflect on their needs in the interim and also the bloods they would be getting checked of that day.

So not only would I go through the test that we are doing and explain why it is that we're doing and to put them into the trend that we've seen from previous tests, but our nursing team then whenever the patient comes out, our nursing team then would go through and reiterate the same tests and explain that also to the patients as well.

Q. Have you ever had cause to test for a particular virus, for example, a parvovirus or something similar?

A. Yes.

Q. If so, would you have a different consent process,

a more formal consent process, of something like that?

A. So my job as a consultant haematologist with a special interest in coagulation, on a routine basis HIV testing and hepatitis C testing is part of a standard block of tests that are discussed with patients, for example, who may present with a low platelet count.

Parvovirus would be not an uncommon test that we would often undertake in our obstetric clinic with regards to women who may be a little bit anaemic due to the parvovirus complications.

So it's discussed openly. Again, it's been already previously highlighted through our Monday MDT with the nursing team. So patients are explained that they'll come with a problem, we'll take their history and we reflect on it and take their additional tests and risk factors and discuss it with them, and then they are informed with regards to the test we would be doing and if that included an HIV or hepatitis screen, the patients are informed of that and they are informed that it would be deemed as a routine test for then. As and when the results are back, patients can be informed directly with regards to the results, because often the discussion will cause anxiety. Despite there being no risk, patients would be very concerned with it and then the nursing team as well

would repeat the similar conversation.

Q. Can I --

A. There's no documentation with regards to a signed consent but with regards to the documentation of the consultation, as well as the letter sent out to the GP, there's open declaration with regards to the tests that are done. Currently in Northern Ireland all of our records are held in an electronic care records system and that is open to any healthcare professional that can go in, and there is a link with regards to all blood tests that have been undertaken serially in any individual patient using their healthcare number.

Q. Can I clarify one point there: are patients informed that the test is going to be undertaken or is there a discussion it can be undertaken and they're consented for that, because your answer suggested that they were simply informed?

A. Yes. So, no, you're quite right. So with regards to the tests, they are discussed and that we would go through them and if there are any issues or concerns or anything from patients' perspective with regards to what it is that we're testing them for, that they have that opportunity to raise it or to discuss it further.

Q. I understand that the centre no longer stores blood samples on a routine basis apart from in relation to

the genetic testing?

A. Yes, that's correct.

Q. Have you had any discussions with patients about previously stored samples and whether they were aware of samples being stored historically?

A. So with regards to the terms of reference of the Inquiry, and watching the last two days, I'm certainly aware of those types of discussions that have been highlighted and come to the fore. Those patients who have submitted their statement have also reflected with myself and the team over that period of time with regards to their observations.

Q. What have patients been saying to you about their knowledge of stored samples?

A. Well, as with regards to their statements, I suppose that had been provided that some --

Q. Sorry, I'm not meaning the statements that the Inquiry has received. I mean in conversations that you've had with patients.

A. Okay. Well, most of those conversations in recent times have been with those individuals who have submitted their statements to the Inquiry. I think with regards to stored samples they have reflected on those, those who have requested their medical notes today seem to be the ones who are discussing it more

with me and highlighting things with me and have contacted us in the recent times with regards to storage of their samples historically.

Q. I understand from your statement that all the patients at Belfast had been tested both for HIV and hepatitis C. All the patients with haemophilia and von Willebrand's had been tested for HIV and hepatitis C by the time you arrived at the centre.

A. Yes.

Q. Do you recall any conversations with, for example, Dr McNulty or any of the other staff about that time and about how events had been managed in relation to the testing for HIV and hepatitis C?

A. I think many of the patients had reflected with regards to the epidemic with hepatitis C --

(Connection frozen)

MS FRASER BUTLIN: We've lost Dr Benson again. Hopefully he will return.

A. -- conversation.

MS FRASER BUTLIN: Sorry, Dr Benson --

SIR BRIAN LANGSTAFF: We lost you at the point where you were just talking about the epidemic of hepatitis C, they'd reflected on that, and then we froze.

A. So the patients themselves have reflected on their lived experience having come through the epidemic and

the infection of hepatitis C and HIV. I think I've not had any discussions specifically with any of them with regards to the specific topic of consent or what they were informed or what they were told. I think their reflections, as with mine, have been more of a pastoral nature in understanding the effects on them rather than the event itself.

MS FRASER BUTLIN: Sir, I'm about to move on to a different topic. I wonder if now is a good moment to take a break.

SIR BRIAN LANGSTAFF: Yes, I think it probably is. We normally take a break, about half-an-hour, in the morning as you will have seen from the last couple of days. So let us take a break now and come back at 11.50.

A. Thank you.

(11.20 am)

(A short break)

(11.52 am)

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: Dr Benson, we heard yesterday that there were 16 patients of the Belfast centre who were infected with HIV, as well as a partner of a patient, and when you arrived you said in your statement there were just three patients at the centre with HIV.

A. That's correct, yes.

Q. Do you know whether any of the other patients had moved away from Belfast or whether they'd all, sadly, passed away?

A. *(Unclear)* all patients passed away by that time.

Q. As far as you were aware, were all of those people who were HIV positive also co-infected with hepatitis C?

A. I believe that the majority -- whenever the Skipton Fund had been updated to go back to the predeceased patients and to see if we could avail of extending out the financial scheme to them, I had made endeavours for at least one of those patients who had predeceased to find evidence of hepatitis C infection, but they were not able to, through extensive trawls, to be able to prove that, but of those that I am aware, yes, most are co-infected.

Q. In terms of how HIV treatment is managed, can you tell us what the position was when you arrived at the centre?

A. Absolutely, yes. The position at the time of my arrival continues to be exactly the same is it is today. Dr Say Quah, who is a specialist in HIV medicine, was appointed, and as part of his appointment the haemophilia patients were specified as part of his ongoing review and care. So Dr Quah will

come across the haemophilia service on a regular basis two to three times a year and the patients are seen there with him, and all prescribing of the medication is managed by him and his department.

The haemophilia service will attend to the patients with regard to their routine bloods ahead of Dr Quah's clinic to ensure a smooth transition of the patients, that he has all that information available at the time.

Q. How do you interact with him in ensuring that the treatment is holistic?

A. Yes, I think that certainly from my perspective it's always important to be up-to-date with regards to the treatment, because I think sometimes there may be unexpected side effects or things that the patients themselves will often signpost themselves for the haemophilia service. So I'll see Dr Quah whenever he comes across to the clinic and we'll have a meeting or a refreshing -- or a refreshment with regards to how things have been for the patients beforehand, and then also a discussion afterwards. Notes are recorded in the patient's notes, so it is possible then for me to be able to go back at those at later stages as needed.

Q. Is there a difference then between what's provided for those patients who are seen by Dr Quah in the

haemophilia clinic compared to what they would otherwise have been provided with in terms of multidisciplinary care in an infectious diseases clinic or a GUM clinic?

A. So the only model, unfortunately, that I'm aware of is the model at the haemophilia centre, which was the same -- even whenever I was a registrar. I don't know what the remit of the infectious diseases clinic would be.

Q. And in relation to hepatitis C, can you recall what the numbers of patients were who were infected with hepatitis C at the centre when you arrived?

A. Yes, I think that historically -- I think it's a part of my statement that we provided that there was a record, about three pages long, that was found in the filing cabinet, which we sort of had extended to around 99 patients that we believed had hepatitis C PCR positive. At the time, in 2008, there were approximately between 20 and 25 patients who remained hepatitis C PCR positive at that time, and as of today the situation is there is one patient who remains hepatitis C PCR that have been seen and assessed and offered their therapy and they have currently taken the decision to wait.

Q. And in relation to that list that you found when you

arrived, if we have a look at it, WITN3082023.

It's obviously all been redacted. There's nothing on this list which indicates when the testing took place. Was there anything --

A. Yes, that's correct. That's my handwriting. So there are patients there that the PCR was negative and genotype negative. So at that time point it was negative. My annotation beside that as positive is that a subsequent test was positive.

Q. When you were trying to establish the situation with your patients, did you find any other documentation that gave you any indication of when testing took place and any dating for it?

A. No. As I said, the exercise that I had to take part in with regards to the review of the Skipton scheme for the predeceased, the only other resource that I was able to undertake was with the then head of the virology department, Dr Peter Coyle, who I had asked to do a search through the laboratory system to ensure that if we searched under the source code using Dr Mayne as well as the haemophilia centre code -- what records they may have of PCR testing, to try to get a more complete picture to support families with regards to their access to the enhanced scheme. But this was the most contemporaneous record that I had at

that time with regards to the patients, as well as, as I met the patients themselves, to review their own medical records and share with them their past experience and those who were hepatitis C then negative.

Q. Thank you, Soumik, that can come down.

You've obviously annotated that note we just had up there with your own handwriting of people who were then positive. Does that suggest you also retested people?

A. No. So historically whenever I started and I went through that list, then I knew of the subsequent patients after having seen them or based on my own direct conversation with them that they were positive. In the last 13 years one patient with regards to bleeding disorder hasn't tested as hepatitis C positive. He was a young gentleman who chose Northern Ireland as his new home, as he had travelled to us from Europe, and he had previously known to be hepatitis C positive.

Q. And when you first met the patients, on your arrival, what do you understand that the patients had been told about the risks of transmission to others? What was your sense when you were talking to them of what they knew?

A. It's probably a little bit mixed because probably whenever I met them all for the first time it was for me to express to them the understanding and to refresh it and to update it. Clearly, as their new consultant, I became responsible with regards to their ongoing care. So I think with regards to -- most of it would have been more refreshing, with regards to the risk of blood transmission, the low risk with regards to sexual transmission -- but it was not a zero risk -- with regards to hepatitis C, and that would have been my routine stance with regards to the patients that I had seen at the start.

As to what they would have been informed historically, I would not have any knowledge of.

Q. So you discussed the issues with patients afresh when you first met them. When you did that, did you get the sense that this was new to them or that this was something they'd heard before?

A. On reflection, I can't -- it did not come across as being anything alarming. It did not appear to cause any undue distress to any of the patients whilst it had been explained to them. Whether or not that was because of how they had previously been consented or their basic awareness or just how it was delivered to them on that occasion.

Q. Now in terms of the provision of treatment for patients with hepatitis, Dr Anderson in her statement has indicated that a weekly joint hepatology and haemophilia clinic was established from 28 June 2004 once Dr McDougall had completed specialist training in hepatology. Was that what you found when you arrived at the centre or had things changed?

A. That wasn't the picture at the centre whenever I arrived in 2008. In a true sense, a combined clinic will involve a hepatologist, a haemophilia doctor in the same room with the patient. At the same time, at the stage in 2008, the vast majority of patients who were hepatitis C negative continued at the haemophilia service. Those who were positive and had had previous standard first line therapy in the form of pegylated interferon and ribavirin and if they had not achieved a sustained virological remission, or if they were on a hepatoma surveillance programme or pending a liver transplant, were all looked after at the Royal Victoria hepatology service.

The cohort of patients that remained within the Belfast centre, as had been the practice even as my time as a registrar from 2003, treatment was delivered on a -- it was -- I'd describe it as a share and care basis, we used the same protocols and the paperwork

that the hepatology service would have done, and patients would have received their pegylated interferon and ribavirin at subsequent follow-up and blood tests through the haemophilia service with regards to their first line treatment.

So I'd overseen the treatment from 2008 up to approximately 2014/2015 of ten patients -- well, ten courses of treatment involving pegylated interferon, of which, as you're aware, one patient was treated twice during that time-frame.

Subsequent to 2016/17, whenever the NICE technology appraisals that come online with regards to the newer treatment, the remaining patients who were still hepatitis C PCR at the Belfast centre were referred en masse, all together, and at that time there were 13 patients, one of which had just started his treatment, because it was known to hepatology. There were a further two patients who had chose Northern Ireland as their home and who were hepatitis C positive, and that remained -- ten patients then referred over to hepatology automatically.

Of those ten patients, or subsequent to it, treatment was offered to patients and discussed openly with them. What I did find at the time was a lot of

patients saying that they were well or a previous attempt at treatment using standard interferon had been provided to them and they had significant side effects from it and at that time were not keen to take treatment. But reflective of the practice from 2008 to 2015, that treatment was constantly refreshed and reminded and updated to all patients at all occasions.

Q. I just want to unpick that timeline a little bit more in detail. In relation to the initial period, around when you arrived at the centre, if we could have a look at the UKHCDO audit from 2009.

WITN3082026. And if we turn to page 11, we can see about halfway down the page at paragraph starting "Twenty patients" -- a little bit further down.

"Twenty patients are HCV infected (3 co-infected). Half are managed by Dr McDougall at the Royal Victoria Hospital whereas the others prefer to be managed on the unit. Unit staff directly co-ordinate HCV combination therapy for these patients with the full support of Dr McDougall. If there are any concerns regarding the patients managed by the unit they are referred back to the Royal Victoria."

In that part of the audit it suggests that the patients had a choice of whether they were managed by Dr McDougall or whether they were managed on the unit.

Is that right?

A. It's not so much a choice given to the patients other than the choice that they themselves had made. Largely some patients, and even to this day, feel that the Royal Victoria Hospital has been responsible with regards the infections that they acquired and had found it very difficult to contemplate to be referred back there, often citing that that's where it all started.

Other patients have had perhaps negative experience in the past with regards to a previous hepatologist, which again many had reflected, as well as I think that they felt more comfortable within the City Hospital with the team that they already knew, knowing that the standard treatment protocols were there.

I think one of the main advantages with regards to the haemophilia service was no delay of treatment. So as and when patients were discussed and they were keen and open to receiving their treatment, information was provided to them and we can start then within a day of them having made that decision.

Q. I think in your earlier answer you indicated that there was a sort of clinical basis for who was dealt with by Dr McDougall and who was dealt with within the

clinic?
A. Yes, so not a particular clinical basis. I think that we looked at the actual populations themselves. That was largely how the cohort of patients had split themselves across. So those with previous treatment who there were no other therapeutic option available to them, the vast majority of them had fallen into the Royal Victoria Hospital follow-up. I think largely with regards to the follow-up or new treatments coming out. So whilst the haemophilia service had provided pegylated interferon and ribavirin in that follow-up, the newer therapies and new education and information would have been made known through the hepatology service first, as well as through the haemophilia national, international meetings with regards to the newer treatments that came out subsequent.
Q. We will come to the newer treatments in a moment. I just want to stay in this period when we're dealing with pegylated interferon.
I'm still not clear, Dr Benson, whether you are saying the patients were given the option, whether the information was provided to them and they chose whether to be treated by Dr McDougall or by the clinic, or whether you are saying actually that was

a discussion you had with Dr McDougall and you sort of divvied up the patients yourself?
A. No, there was no discussion that I had had with regards to dividing patients between which site that they would require the treatment on it. So as and when the patients would come up, because ultimately all of the patients with regards to their bleeding disorder were reviewed at the clinic, then the treatment was discussed there. From my perspective, at no point did I refer anybody across to Dr McDougall and his team for the primary purpose of treatment with pegylated interferon and ribavirin.
Q. In terms of the support of Dr McDougall for that cohort of patients who were treated within the clinic, what did that constitute? How did that work?
A. So we have very open communication channel even today with regards to hepatology service. So with regards to the patients the paperwork that had been provided, worked on from the service, having taken over the treatment so prior to my appointment, and how pegylated interferon is prescribed and followed up and discussed. So all patients are discussed and there's a hepatitis C database that was maintained by the hepatology service. We had regular meetings with Dr McDougall with regards to patients and patient

progress, and any concern with regards to any of the blood tests that any of the patients had presented with, or that the patients wished to have any further discussions then we would have had that discussion directly with Dr McDougall.
Q. In those early years, did you explore re-establishing a joint clinic with a hepatologist?
A. I had felt that at the time that the service itself had started off, as my understanding had been, as a joint service and, for whatever reason, the full history of which is not known to me, that the combined clinic service had stopped or had felt to be that an alternative way was better or sought and that's the service that was there in 2008.
Q. But did you take any steps to consider or explore the possibility of bringing that into the haemophilia clinic as a joint clinic?
A. Yes, we had those discussions with regards to it, I think with regard the communication and everything else seemed to be working okay and there was no issues with regards either from the patients or Dr McDougall or the clinical or nursing staff with it. But we had had those regular discussions that had never really come out of it to say that it needed to be re-established.

Q. What information and advice were you able to provide to patients about lifestyle factors, such as diet and alcohol, in the management of their hepatitis C?
A. Yes, so it was a very clear challenge that we had had from 2008 with regards to some of the men, particularly with regards to alcohol. So in discussions with Dr McDougall and sharing that along with the patients we appreciated the fact with pegylated interferon and ribavirin the success rate is lower for hepatitis C eradication but also the side effects are much more significant.
One of the other challenges that we had previously alluded to was really a disengagement from the general review protocol from the clinic, in patients really coming and being reviewed and being adequately followed up.
So, from our perspective, at each opportunity that I had with regards to patients face-to-face was to try to be open, discuss the availability with regards to the treatment and highlight, really, the long-term outcomes that maintaining hepatitis C positivity was there. Many of the patients would have noted it and taken it on board. They, as I said previously, would have felt well and they wouldn't have felt an advantage in the shorter term with

regards to taking their treatment. The discussion was open. It wasn't given as a coercion, I was always very minded to try to make sure that I didn't exacerbate the disengagement any further with regards to people then thinking that every time they come up to the clinic that all I was going to do was to try to ensure that they took their hepatitis C treatment, but certainly with regards to alcohol was an issue.

What we would have done would be to try to signpost patients with regards their alcohol intake and to see if there was anything extra that we could do to help to support them with that. Several of the men were very receptive to that, both seeking their own family support, and I remember several of them coming to the clinic with either their children or with their sisters, in order to help them through a period of abstinence, to allow them to be able to take their treatment.

It was clearly very difficult for many of them and the success rate was good, with regards the abstinence, but I think that, in the longer term, they really did struggle both to regard their mental health and with regard to their family relationships.

Q. In that regard, did you consider referring patients on, was there anyway you could refer patients on for

additional support in that?

A. Absolutely, and it would be with regards to support either through primary care or through addiction counselling. At that time, I had undertaken some training or, sort of, course -- not a course but with regards to motivational interviewing. I think it's all well and good that I can see a challenger problem with the patient but if the patient can't see that problem themselves -- so I was trying to tackle it with going through a motivational and positive way for them. We do the same with regards to smoking and obesity but it was a particular challenge, as it is for the Northern Ireland population in general with regards to alcohol intake.

Q. When you were discussing the advice around diet, and particularly, as you say, alcohol, was it your sense, was it your impression, that this advice was new to the patients or something that they had been informed about before?

A. I think on most of the occasions it would certainly come across as something that they had been aware of. I think perhaps less so in diet. I think at that time in 2008 and moving forward with regard to obesity, it wasn't such a significant occurrence or issue that perhaps the centre will face with their patients

today. But, at that stage, definitely with regards to alcohol and the exacerbation of the hepatitis C virus, that cirrhosis was more of a significant and an accelerant challenge for them.

Q. You just said that you oversaw the treatment, the giving of ten courses of pegylated interferon and ribavirin, what information did you give patients about the side effects of that treatment before they started it?

A. So there were drug-specific leaflets that had been produced and provided and the patients were given those in relation to their ribavirin capsules and also their pegylated interferon. I think from firsthand knowledge there's a registrar going through the service and seeing the patients on the treatment, mood and it was a common challenge that the patients will face, and the advice with regards to a prophylactic antidepressant being advised. Generally, that was my preferred route for patients given the time-frame that's required for an antidepressant to get into the system before it starts to work, rather than reviewing them after two to four weeks and then finding that they are already being challenged with regards to their mood at that stage.

So I think that the side effects of mood change

and mobility in mood, as well as a constant flu-like feeling, will generally tend to be the commoner ones. The other one, obviously looking after young men, was the impact of the ribavirin and teratogenicity with regards as to having children and, indeed, on one occasion of those patients who were treated at the time or treatment was selected at a time that his wife was pregnant for him to be able to take that treatment.

Q. In addition to prophylactic antidepressant medication, since you didn't have an embedded psychologist within the clinic, was there any scope for providing any more structured therapeutic intervention for those who were struggling with low mood or depression?

A. So we had access to the haematology social worker, with regards to support in that service as well as signposting through their own GP to see if there's anything more convenient or local to them.

I generally found a lot of it was acknowledging the fact of the side effects that they had had upfront, acknowledging what they were going through and what they were facing, and the challenges and the struggles of it. I think certainly those men who had had previous history treatment with regard to standard interferon were much more receptive with regards to

the discussions about the antidepressant, being minded of the side effects that they had previously suffered from.

Q. Now, you have indicated that once the newer non-interferon based therapies became available the mode of treatment changed. I think you gave the date as 2016; is that right?

A. I think with regards to the last course of the pegylated interferon was 2014/2015. The discussions then at that stage with the hepatology service were in line with regards to the non-pegylated interferon based treatment, in line with the NICE technology appraisal. So, as you are aware, some of those were less -- stipulated early on that you had to have a previous course or trial of pegylated interferon and ribavirin and be resistant to it before you became eligible for the next line, or the second line.

So I was very much aware around about 2016/2017 that letters and -- well, further to the discussions with the hepatology team and Dr McDougall, we had a discussion, given the fact that the previous provision of treatment through the haemophilia service, whether or not that would be something that would be considered. Neither of us felt that that would have been appropriate, based on the level of

knowledge with regards to the newer drugs and the monitoring.

There had been enhancement to the hepatitis C service with regard to the additional nurse specialist that had been provided there. So, at that stage, with regards to the newer treatments, then patients started to receive them, with regards to those who had known cirrhosis or challenges or derangement in their liver function tests and then at which stage then the patients that remained at the haemophilia service were then referred all together.

Q. Are you aware of there having been any delay in Northern Ireland in accessing those newer drugs, compared to the rest of the UK?

A. None that I'm aware of, and I certainly think that with the discussions with Dr McDougall at that stage that the service itself had prescribed many of the medications from the technology appraisals from NICE, in advance of the NICE being published.

Q. Now, in terms of current care, you've indicated that the hepatology service managed patients who have had a liver transplant?

A. That's correct.

Q. But the transplants themselves, we've heard, take place over in London?

A. That's correct.

Q. Presumably, you are not involved in any way in any of the assessment of patients for referral to King's?

A. I would be involved with regards to sharing of the information of the bleeding disorder, the clotting factor concentrate that the patient would have been receiving and any past complications, such as inhibitors, or something that the haematology service at King's would require. So, as part of the referral, there would be a haemophilia summary that I would write and provide for those patients.

Q. In terms of patients who have developed cirrhosis, you've indicated they are also managed under the hepatology service. Do you know what ongoing monitoring and care is provided through that service?

A. The hepatoma surveillance service is a six-monthly ultrasound scan which is organised through the hepatology service and on the day of the ultrasound scan being performed, a serum alpha-fetoprotein is also undertaken for those patients. They continue to have their haemophilia and other bloods checked routinely at our own out-patient clinic but the hepatoma surveillance programme is the ultrasound scan and that blood test.

Q. How do you co-ordinate between the haemophilia team in

and the hepatoma surveillance clinic?

A. So the hepatoma surveillance clinic is run on an automatic, six-monthly basis and the hepatologists will get those results and, if necessary, get additional scan or review of the patient should the ultrasound scan show any change or anything different from previously. From the haemophilia service perspective, the patients continue to be monitored at their six-monthly or annual basis as they would do normally for their underlying bleeding disorder.

Q. Are you aware of any patients, any of your patients, who are under that hepatoma surveillance programme raising concerns with you about their care? Have you had any of those sorts of conversations where patients have come back and said "we're concerned"?

A. About care with regards to their hepatology care or with regards to their haemophilia care, sorry?

Q. Sorry, in relation to their hepatology care and particularly in relation to access to FibroScans?

A. So FibroScan is something that, more recently, has become the routine nature of the hepatology service and is largely utilised for patients for the hepatitis C treatment. As far as I'm made aware, it helps to differentiate between 12 weeks or 24 weeks. Patients have raised with me, those who have

undertaken their hepatitis C treatment and, as I say, there's only one patient who remains hepatitis C positive. Patients over the last year or two have contacted me in Access and queried whether or not they can get a FibroScan, we have discussed that with the hepatology service and, based on those requests, that has been facilitated.

From a hepatology perspective, it would not be a routine follow-up scan for patients at this stage.

Q. I just want to clarify as between two different groups of patients, firstly the patients who do have cirrhosis, do they have a routine FibroScan?

Sir, I'm afraid Dr Benson has frozen again hopefully in a couple of minutes he will return?

SIR BRIAN LANGSTAFF: We are back. Ask the question again.

MS FRASER BUTLIN: Thank you, sir, I just want to clarify between two different groups of patients, firstly the patients who do have cirrhosis, are you aware of whether they do have a routine FibroScan?

A. With the diagnosis of cirrhosis, a routine FibroScan has already confirmed the cirrhosis. So those patients who are on the hepatoma surveillance get a six-monthly ultrasound scan, as I am aware.

Q. In relation to the patients who are now PCR negative

and haven't developed cirrhosis, how is their condition managed and monitored?

A. Their condition's monitored with regards to their haemophilia routine bloods that we agree to check with them, and monitoring and follow through with regards to liver function tests.

Q. Is there --

A. As for the hepatology service, there would be no routine need for service in place with regards to FibroScanning patients who are not hepatitis C PCR negative.

Q. I think you said earlier though that if a patient raised particular concerns with you, that they were concerned and worried, that in some situations you have then arranged for them to have a FibroScan?

A. I haven't arranged, I've signposted them to the hepatology service and then they can have the indications and needs of that discussed with them and then to undergo the FibroScan with them.

Q. Do you know whether patients have been able to access that through the hepatology service?

A. Yes, there's been no issue with regards to any of the patients that have been referred at their own request through me to the hepatology team. They are very happy and willing and very capable of undertaking the

test, and have done.

Q. In relation to the patients who have had treatment under the haemophilia clinic previously, so in the pegylated interferon ribavirin times, is there a group of patients who have never had a FibroScan because they were cared for under the haemophilia centre for their treatment and they are now PCR negative; is there a cohort of patients who have not had that access?

A. Yes, but it's not because they have been looked after by the haemophilia service to have their treatment, it's because historically they have had their treatment prior to the availability of a FibroScan, which has only been, I think, the last three to five years. So there have been -- over half of the patients had standard treatment 10/15 years ago.

Q. So, in terms of their ongoing monitoring, that's provided through liver function tests?

A. Yes, and full blood count to check the platelet count.

Q. The Inquiry's heard evidence that many people in that situation remain very anxious about the condition of their liver and a very real fear of the hepatitis returning. How do you address those concerns within the clinic?

A. I think for those patients, you're quite right, it is

a real concern for them. I think from our perspective it's to go through the blood results that they have had and to show them where they have been with regards to the tests and the reassurance that those tests are within the normal range and there's no signal or no concern that is being highlighted from them.

Q. Going back to what we were discussing a moment ago, if they asked you for a FibroScan to check, you would refer them to hepatology?

A. Yes, if a FibroScan came up but, equally, if their level of alarm or concern is significant I wouldn't wait for a patient to ask me to access a FibroScan. We would be in a position to be able to refer on, and have the discussion with hepatology, with regard to their access to it and equally for them to provide the same reassurance that we are doing.

Q. Are you aware of any gatekeeping done by hepatology which would require particular liver function test results before giving a FibroScan or is there a sense of enabling patients to have a FibroScan in these circumstances, even if perhaps the liver function tests are not indicating there was a need?

A. There's absolutely no gatekeeping whatsoever. If we feel that there would be a great amount of positivity or reassurance provided to a patient or to their

family, the hepatology team are more than willing and able and have done and provided the scan, and some patients on multiple occasions for reassurance.

Q. The Inquiry's also heard evidence from a number of witnesses who, although they've been treated for hepatitis C and they are PCR negative, have continued to suffer from very considerable ongoing symptoms and difficulties. How is that managed within the centre?

A. So I think with the multi-professional team that we have it's to look at the specific symptoms. I am aware of, in a number of individuals, as you have also highlighted, symptoms such fatigue and ongoing joint pain and concentration. So the long-term, sort of, multi-systemic effects of hepatitis C and just bearing those in mind and taking them forward, so be that through support with regard to their joints, social work support with regards anything additional that they can be provided with, occupational therapy, counselling in relation to talking issues through, are all available with regards to patients.

Q. Now, I want to move on to vCJD. You said in your earlier evidence that vCJD notification was one of the issues that patients highlighted in the survey before you arrived in Belfast. Can you tell us a little more of what the themes of that were?

A. Yes, absolutely. It's quite distressing. I know with regards to the letters, I think that for those -- some men kind of feeling what's next and that it really established an element of mistrust, I think, with regards to all that they had already come through, and then variant CJD being added to that, with regards to a risk. I think the challenge of not having a blood test for it was difficult for many to just be told that, you know, as a public health issue of a risk that you are being told that you are at risk and, for many, this felt really very difficult and a lot of, I think, general lack of understanding with regards to what the risk labelling actually meant to them and what could happen and what can't happen, and various delays and concerns with regards to them trying to access medical care, now with the label there with it.

I suppose some of them had been written to twice, as well, so some of them had clearly felt that this was reminding them of a reminder, or the letter was very difficult, and in some of their records there are handwritten letters from patients to the interim director at that stage of the second write out to try and *(unclear)* the patients, really very clearly spelling out their absolute anger with regards to the receipt of a letter that for many they weren't aware

that it was coming.

Q. Then, in relation to your time at the centre, in 2009 if we can look at the document GGCL0000222_001, please, Soumik. We can see that these are meeting minutes from March 2009 of the Scotland and Northern Ireland Haemophilia Directors Group, and if we go down to page 2, paragraph 4(d), under the heading "vCJD notification exercise", we can see that concerns were expressed about the notification process and, towards the end of that paragraph, "GB reported concerns", which I believe is you, Dr Benson?

A. That's correct.

Q. "GB reported concerns that he was informed by a patient and a WFH representative who knew of the new vCJD information before we as haemophilia directors did and that his colleagues in blood transfusion seemed to have known for 2 months prior."

What can you tell us about this?

A. So I think not that long before this meeting took place, one of our patients who was very into the World Federation of Haemophilia had visited the centre and actually on that occasion had brought with him the then President of the World Federation of Haemophilia, Mark Skinner, to visit the centre and to have a look around, just for a general chat, and it came out as

part of that discussion with regards to an event or a patient who had a mild haemophilia, if I can recollect the subtype that he had well enough, and at post-mortem prions were found within the patient's spleen. So after he had left I thought it was a little bit unusual that they were made aware of that and I contacted our Blood Transfusion Service colleagues again just to try to gauge from their perspective what their understanding or if they had had any particular knowledge and, again, as reflected in the minutes, they also had had it. So it reflects the case and the letter in relation to the patient with haemophilia who had prions in his spleen but did not have variant CJD.

Q. Did that delayed knowledge for you cause particular difficulties?

A. I think sometimes it's just that slight issue with regards to a patient raising their concern or sharing it with you and then being a little bit, you know, unable to provide that additional support or that level of understanding or trying to put the issue into context, what they were discussing. So a patient with haemophilia with prion was not with variant CJD but that it was noted in a patient's spleen and, as such, it was quite a different situation from what was being

shared.
Q. In your statement, you say that the Trust established a vCJD group to manage and identify patients at risk ahead of surgical procedures. Can you tell us how the group went about managing your patients who had been identified as at risk, when they required something like an endoscopy, what processes were put in place?
A. So the World Health Organisation had updated their pre-surgical checklist and had placed in variant CJD risk assessment ahead of procedures. So a group was set up in the Trust, and I was invited to go along with regards to probably having the largest cohort of patients who were placed under public health risk with regards to variant CJD, and to see from the Trust perspective how they were working out a risk assessment form in order to ensure that patients were appropriately being screened and assessed ahead of their surgical procedures.
Q. Now, it's understood that, in relation to the 2009 notification, that you took the decision not to issue letters to patients?
A. The Trust took the decision not to issue letters. The letters came in through the public health agency to the medical director of Belfast Trust, at that stage, and I had a meeting along with the team and the

medical director, and we reflected on the letter that had been drafted and came in through the public health agency and, ultimately, the letter highlighted the fact that a patient with haemophilia had a prion presence in his spleen biopsy or his spleen at the time of post-mortem but had concluded to inform all the patients that this did not change your risk based on what you had previously been told.

So the medical director, along with ourselves, agreed that the letter to go out, given the fact that it did not change risk, was appropriate.
Q. Can you tell us anything about the discussions you have had with patients around this time about vCJD, either in relation to the 2009 notification, which the Trust didn't send the letters out, or in relation to how it's discussed when they have a surgical procedure coming up?
A. Yes. So part of the original letters that went out were also copied to GPs. So if a GP happens to refer a patient in to another hospital for a procedure it forms part of the medical history record from the GP to ensure that it's highlighted to all individuals or surgeons or endoscopists, who may be looking after the patients. In general, we try to do our best to ensure that we centralise any surgical procedures or biopsies

within the Belfast Trust itself, where there is a cohort of individuals who are very well experienced with regards to what is required, but equally that a delay in a procedure is not acceptable purely based on a variant CJD risk.

So the patients will always go through their own standard risk assessment and they will be asked the questions from the nurse doing the assessment for the procedure and it will also form part of our discussion with the team. So, for example, patients who would be getting joint replacement surgery, whilst the patient themselves may notify the fact that they are at variant CJD risk, that actually the surgery itself does not present any challenge with regards to the instrumentation being used.
Q. But in terms of your discussions with patients, how is that dealt with?
A. In that we would recap with regards to any surgical procedure that they would need to get done, that they are aware we don't do the risk assessment ahead of any procedure so that's done centrally with the individuals doing the surgery or the biopsy or whatever it is that's being done, but we would intervene with regards to clarity for the patient, that it's either an at-risk procedure or not, and also

with regards to the person doing it so that they are aware that instrumentation should be disposed of afterwards or if in doubt quarantined in the likes of an emergency procedure until we can clarify it the next day.
Q. As you said earlier in your evidence, there are a number of patients for whom the vCJD notification has caused considerable anxiety and concern. Is there any formal counselling or psychological support that's been put in place to assist with that or is it simply the question of the open access to the psychological service?
A. Yes, so if I remember from yesterday's evidence as had been presented, Dr Julia Anderson had touched on the initial write out exercise with regard to variant CJD, had highlighted the counselling that had been made available and set aside at that time, and that at the time of the first write out that actually no patient had availed of what was made available at that time.

With regards the second write out, I was not there at the time to be able to provide any assessment as to what's there. But the system, as you have highlighted, that the patient has any particular concerns or anxieties or worries, then we are able to signpost them appropriately, either within the team

themselves, if they are happy with that, for either myself or a member of the nursing team, or their social worker if there's any challenge or, indeed, as you are aware, more recently, on to the dedicated psychology team.

Q. Now before I move on to look at medical records, in your witness statement when you talk about patients seeking records recently, you have referred to the hospital trust having an inquiry team made up of senior management. Has it been any part of the inquiry team's work or remit to meet with those who were infected or affected, as a relative?

A. Yes, they have, and they have taken direction from the local patient support group or Haemophilia NI, and they have met the senior members of that team. The Inquiry team itself, with you, with your colleagues, have also met with the team. They have had a tour of where the notes are kept and recorded. They are aware of the methods of the search in trying to locate and to find all records and that that has been shared. But, yes, the medical records team and senior management have met with representatives of the infected and affected.

Q. Then I just want to deal with some of the questions around medical records.

Soumik, could we have WITN4027001. This I Dr Anderson's statement to the Inquiry and there are two passages I want to look at with you, one of which we saw yesterday, but I will put it on the screen in case people weren't watching yesterday.

Paragraph 6.8.23, it's on page 16 of the statement. This is the passage that we looked at yesterday, sir, but I will put it on the screen just for completeness' sake.

"Medical records were handwritten and kept meticulously. There was excellent administrative and secretarial support, and it followed that the filing was good, with the medical records kept within dividers in the case notes, and any written results were filed in separate sections."

That's what Dr Anderson records as what she found when she arrived. And if we go on to page 127 of her statement, paragraph 67.1, this deals -- 67.1(a), this deals with when the centre moved. She says:

"At the Belfast Centre, I moved all the patient archived records, and all relevant blood bank records from the Department of Haematology, Royal Victoria Hospital to the Haemophilia and Thrombosis Centre, Bridgewater Suite, Belfast City Hospital at the time

on the Centre's relocation in September 2001. The records were kept in a locked room within the Haemophilia Centre in the Bridgewater Suite. Old records were kept, to the best of my recollection, at Musgrave Park Hospital Records Department and there were strict instructions that old records must never be discarded owing to the likelihood of patients wishing to review their case records in the years to come."

In terms of when you arrived at the centre, Dr Benson, where were records of current patients kept?

A. So the current active records with regards to patients as Dr Anderson has described are maintained within the admin room within the haemophilia centre. So they are filed from A to Z for all of the patients with all disorders that are looked after by the team.

At that time then, whenever volumes became needing to be refreshed, if notes were getting a bit busy, then old volumes were then placed within the filing system, haematology -- haematology secretary corridor with the other consultants on a separate run for the haemophilia patient notes. But active notes were maintained as described in the centre.

Q. And in terms of old records, were you aware of any

being held at the Musgrave Park Hospital records department?

A. I think with regards to the location of such records, they would not be anything that I would have been aware of, as to exactly where they would have been. I know historical records can sometimes be stored at Erskine House, which is where the old records may be, but there are many places, as I have learnt through the Inquiry and searching for notes and records, as to where patients' records may be stored.

Q. When you arrived and came to treat patients and looked at the notes, were you aware of any gaps in the records or information that you would expect to be in them, were you aware of any gaps in that?

A. No, there were no gaps that I had had whenever I was trying to find the relevant information regarding the patient who was sitting in front of me as I was familiarising myself with regards to their history. As Dr Anderson's highlighted, they were -- meticulous notekeeping with regards to the history of the care the patient had had. The vast majority of them had a very useful summary front sheet which highlighted previous doses and treatments or surgical challenges that they may have faced in the past.

Q. The Inquiry's aware that you have had quite

considerable involvement in trying to help patients obtain records. The Inquiry's heard evidence from some patients and relatives who have described difficulties in accessing records and some who have described your help in accessing records. Can you tell us your involvement in this. What have you been doing?

A. Yes. So the Trust have been tireless with regards to trying to locate records and to support patients as far as what they can be based on the records and the destruction of records, policies. The hospital itself has undergone many reviews with regards to health and social care trusts and boards and various different policies, and I know that Ms Richards highlighted many of those yesterday with Mrs Leonard's statement with regards to record-keeping.

For the vast majority at the start we had had -- any subject access requests that were to come in through me and be signed out immediately to go and to see what records could be found. But really it was, I think, largely a learning process with regards to finding the records. The vast majority of them were to be easily located in the first search of it, and then we -- became apparent that, you know, the searches were repeated, largely because of filing

systems. So if I were to perhaps use my own name as an example, as being Gary Michael Benson, some patients had their records filed because they were called Michael, so it was filed under Michael Benson, but the birth certificate name was Gary. We also found issues that if Gary Benson was searched for and there was a space between Gary and Benson, that was a set of records but if there was no space between Gary and Benson and it was all one word, that was filed separately. So in repeating the exercise of trying to find patients either by their birth name or by their called name or whether there was a dash or a forward slash, the medical record team were really, quite frankly, amazing. And I think that's where some of the -- you know, the initial learning that we derived from the process was that sometimes the tendency on being dried out to go, "We have had a look and we can't find anything", and I think often, based on the wording used, that it should have been a bit clearer by going, you know, "On our first search we haven't found anything. We will repeat it again and we will look elsewhere and we will seek elsewhere", and I think with regards to the policies of destruction and everything that's already been provided with the vast majority of the medical records

that are available to be found have been found. And they are all stored separately, in a separate part of our hospital, and are not touched outwith patients requesting access to them.

Q. In relation to information on patients that have been fed back to the UKHCDO, you have said that in the records there was evidence of past consent to that. Can you tell us what you identified in the records and from what date?

A. So a lot of it will probably cross-reference with Dr Anderson's statement, with regards to the meticulousness with regards to how Dr Anderson had undertaken her work.

UKHCDO had performed a question and answer session with regards to the information on the database and had put that into a leaflet, so the record that I refer to as a historical leaflet filed in a poly pocket in the front of some of the notes with Dr Anderson's signature on it, with regard to the explanation for the patients at that time about data and what was being shared -- or what their data was being used for and being shared. And again, updated by myself with regards to the boys or girls during transition or transfer of care, to refresh their information. Often parents may have been informed

during the childhood but, again, with regards to the custodian of data for the patients themselves, as to -- is to remind them of that too.

Q. Again, when you were undertaking that exercise of checking whether there had been -- whether there was evidence of past consent, did you face a situation where a particular bundle of medical records, a file, one file, was missing or you had some of the files of medical records from the past but not all of them?

A. So the trawl of the medical records as part of the Inquiry I did not on any occasion read or look into any of the information, as I didn't have any consent to do that. So as when the records were pulled and copied and provided to the patients, as and when they were found. The only information that I had with regards to historical use through records is again through the Skipton access and the review of that material. I was aware that there were several folders within a filing cabinet in my office, which dated back quite a considerable period of time and reflected on some of the patients, the vast majority of whom had been HIV positive. So the use of those files were used to support the families with regards to their access to the obtaining of Skipton. All the content in the filing cabinets at the outset of the Inquiry

were automatically copied and uploaded to Egress for the Inquiry's information.

Subject to that, and the time afterwards, I was then asked, as part of the Trust, to go through and to find additional information, particularly for those families who may have accessed and requested letters or things pertaining to the individual. So I went through all of those documents, and anywhere where a patient's name was noted, that was written down and that was provided to those families also.

Q. So, just to be clear, in relation to the UKHCDO consent, you didn't do any look-back exercise to check and you didn't identify any missing --

A. In regard to the active notes that the patients have, they were filed in the poly pocket at the front. Sorry.

Q. Just picking up on your answer there in relation to separate files that were in locked filing cabinets in your office, from what period do you think they probably dated from?

A. With regards to the uploaded Egress, there are miscellaneous discharge letters and I think the earliest has been, if I were to pick a date, in the 1960s. There could be a very early 1963 letter. So they are a mixed bag and hodgepodge of various things,

some of which were put into files relevant to an individual patient and some were just -- I'm not quite sure why they were there.

Q. You have mentioned the exercise in relation to the Skipton Fund that you undertook, and we're going to come back to that in just one moment, but before we do can you tell us what involvement you have had during your time at the centre in telling patients about the existence of the various trusts and schemes?

A. So with regards to the vast majority of all the patients when I had started and the knowledge with regards to Caxton or with regards to the HIV groups and the Skipton, were already very well established. As I had already alluded to, the poly pocket at the front of the notes with the UKHCDO information leaflet, equally the part 1 or part 2 completed documentation with regards to the Skipton applications were also filed and maintained within the patient's records. So all patients who would have had availability at that time to access those schemes I understood that they had already done so.

Q. And you've spoken a moment ago about the situation that arose when the Skipton Fund extended the provision to relatives of those who died before August 2003. Can you tell us how you went about

seeking to identify relatives who should be informed?

A. Yes. I found the whole thing quite difficult, I think, with regards to largely the communication and the face-to-face meetings with families from whom we have no ongoing contact or communication because no other family member attends us. The group were largely identified, as you've highlighted, through the list of hepatitis C positive patients that was in the filing cabinet. So I was able to utilise that list and to see and cross-check with regards to death histories of those individuals before Skipton came into place, as well as contacting virology laboratory to see if they were able to provide a simple search with regards to hepatitis C PCR testing and what was positive and what was coded at that time to, I think, around the code with regards to Dr Mayne as well as Dr Jones and to see if there was any additional information that we had.

The first --

(Connection lost)

SIR BRIAN LANGSTAFF: We're stuck, I'm afraid.

MS FRASER BUTLIN: We're stuck.

A. -- and we had the information --

SIR BRIAN LANGSTAFF: Just pause, because we lost you.

We lost you at the point where you said:

"... with regards to Dr Mayne as well as Dr Jones and to see if there was any additional information that we had."

And then there was a freeze.

A. Okay, sorry.

So that allowed me then to work out who may still be under active review or any other family members, and we discussed it at that time with the team. So the team at that time had been -- the established team that been there for some time and had also worked along with Dr Mayne and Dr Anderson during that time-frame, so their information was very helpful and supportive of it. So for those patients that we had active still on our list, should it be a grandson or a daughter, those patients were contacted in an appropriate way with regards to the change in the Skipton and to say that we believed or I believed that there was information that we would have that we would be able to help them and to support them in their application for their part 1.

The challenge, though, with regards to anything beyond the part 1, particularly for part 2 application, is the paperwork in order to prove evidence. And the commonest way that this is only ever applicable or available is if it's noted actually

on the death certificate. Medical records for those patients were not always available, or were not available, unless there happened to be miscellaneous letters within the filing cabinet pertaining to those individuals. So we approached families and we encouraged them to come up. It was really very difficult. I think that -- I remember one occasion, a mother coming up in relation to her son, and I found the consultation challenging in talking to her about her son because he was only a few years older than what I was, and I just kind of felt that no matter what the compensation or whatever the money may have been, what this woman wanted was her son, and for me to come, 20 years after he had died, it was just not -- it was just not good. Sorry. She's never -- she's never left me. Just ...

So as far as possible we went through it. It was a very difficult time for many families. I just felt, to sit there in front of these exceptionally dignified people, and for me to offer them a bit of paper to sign, and that I'd sign my bit, and that they would get a cheque, it was just awful.

So it was really a pivotal moment, I think, for me professionally. But they were so good. You know, I got a thank you letter or they thanked me afterwards

for absolutely nothing, absolutely nothing.

Just ... a total waste. Sorry.

MS FRASER BUTLIN: No, take your time.

SIR BRIAN LANGSTAFF: Take a moment. There is absolutely nothing to apologise for. Just take a moment.

A. Okay. So the information, then, that was used, and we tried to encourage as many. I think that over the years, even I think up to about two years ago, I think, I came in contact with another family, and we were able to have that information for them. So there have been I still think -- from my understanding, still at least one other individual family from my perspective I'd be very keen to meet and to support them in relation to that exercise. But that's been something that perhaps -- the grandson has just transitioned across to us and then suddenly the discussion with the mum and then discovering her maiden name and then going, "Oh, you know, I have this -- somebody's name on my list, do you know this man?" And then it turns out to have been her father. So, yes. Sorry.

MS FRASER BUTLIN: You have answered my next question, Dr Benson, of whether you felt you'd managed to identify the families of all of those who had died, but clearly you still think there is at least one more

family who you haven't had contact with?

A. Yes. I think even, you know, the detective work, that there was one mum that we got in contact with her because, rather randomly, her sister had been referred for another reason into the haemophilia centre, and then she was able to share about her nephew having been a patient and then that's how we found the mum and she came up.

Q. The Inquiry heard a lot of evidence when we were over in Northern Ireland of the stigma and the secrecy that was involved in patients having hepatitis C. Before you contacted family members, did you give any consideration to whether families had in fact ever been told about the patient's infection or whether that had been kept from them. And if so, how did you deal with that?

A. Yeah, I think that the vast majority were aware. I think that how families shared that outwardly, as you have highlighted and as was testimony -- a lot of our patients' stories two years ago, whenever you visited us -- is how families shared it. Families were aware within theirselves and within their own home but on occasions they were less so with their extended family member.

At the time of trying to identify the vast

majority of patients, I also had my colleagues in the centre who were there at the time with regards to the death of the individuals and those men and women, so they were able to highlight that also to me with regards to what was known.

Q. I want to move on, Dr Benson, to pharmaceutical companies. You've told us in your statement that pharmaceutical companies provide centre staff with updates on their products but have no influence locally over decisions given the central tendering. Has the centre received any funding from pharmaceutical companies in your time there?

A. Funding has been made available through several of the family days. So Roald Dahl Foundation, as I have highlighted for the initial one, had sponsored that and, with regards to the second day, each of the Factor VIII companies had provided a nominal sum of money of £500 towards the support of it -- of that day. The vast majority of the remainder of the day was paid through the haemophilia centre fund itself.

Q. Have clinicians received funding for conferences or travel or anything like that?

A. I think with regards to support for educational meetings they have been made available and they would be things that from time to time that may be suitable.

As the single-handed clinician I don't always have such availability of time as regards to them but, yes, as part of an educational service, we have been.

Q. What do you do personally or what do you do at the centre to guard against any risk that companies contributing to the centre's work, that they don't influence the decisions you make about prescribing products?

A. Part of my additional role is on the drugs and therapeutics committee of the Trust and, as part of that, there's a declaration of conflict of interests as too there is also for UKHCDO, also for taking part in the CMU accreditation with regards to the tender process, so that there would be a standard way that we would do that. The trust itself has its own policy with regards to accepting gifts both from patients and relatives but also from external bodies and the trust has a policy with regards to pharmaceutical companies and their visitation on site and their interaction with us as healthcare professionals.

Q. You have noted in your statement that you have participated in research that was sponsored by pharmaceutical companies in relation to new product development. What was the nature of those new products? Was it related to blood products?

A. No. So it's a current global trial that's being investigated and it's at -- we were involved at the phase 2 stage, now it's phase 3, of a non-factor replacement product, so rather than Factor VIII. So we have correlated with four patients who are recruited to that trial, two of whom have received the trial product, which is administered as an injection underneath the skin.

Q. Just a couple of final matters. The Inquiry's aware that there may be some patients who feel they have lost trust in their haemophilia centre and in other parts of the UK they may have changed centre. Given the geographical context of Belfast what arrangements would be made for any such patients?

A. So, with regards to patients transitioning out or moving, I suppose there's a routine situation for our students and student sharing. If an individual patient is not content with regards to the service that is being provided then extra contractual referrals are a routine Health Board provision, that patients can be referred to another provider, mostly within the United Kingdom for ongoing provision of care.

Q. So in a Belfast context where would that be to?

A. It can be left open with regards to the family

themselves, but the vast majority are -- well, on the one occasion that has been, that would be to a London centre that the direction was made.

Q. You've discussed your perspective of the impact on patients and families of the infections with HIV and/or hepatitis through blood products. Can you tell us what you have observed in your interactions with these patients and their relatives of what the impact has been on them?

A. I think that if I go to 2008, whenever I started and having met them all and seeing them now within the lens of the Inquiry, I think that the Inquiry itself has given them that opportunity, I think, to go back to when the discussions had happened and almost to relive those years, but as an older version of themselves looking back at the younger version. I think for many years -- I think my statement will allude to the wife of a patient whose really has summed it up quite significantly, I think for me, and it sort of resonates over a long period of time, in that their life has been like a snow globe, you know, the snow has laid thick and it doesn't move and everything is all very controlled, and that's the way that they have just left it.

So in 2008 there would have been open

discussions with regards to, as I am with you now, with the patients and then to see where they're at, but I think that now, on retrospective and looking back and with the appropriate attention that's now being given to what has happened in Northern Ireland, that the globe has been shook and then all of a sudden the snow itself is whirling away, so any control or any reminding oneself to suppress a feeling or to suppress a thought has gone, and it's very distressing and they feel that control is lost and it's difficult.

Q. You have also said this has had a profound effect on your professional practice. Again, can you expand on that forus?

A. Yes. I think that as a consultant whenever you inherit your entire patient cohort you're very much reflective of the fact that inheriting this cohort they didn't start with you, and there are many challenges that have arisen for those patients and, as we'd said at the outset, between mistrust and disengagement and to try to bring them back on board I reflected on many occasions whether or not there's something that I have done or that I have contributed in some way to anybody's care that has not gone as I would have expected it to, in what way can we improve the care or make it better for individuals.

But I just think -- I mean, as my testimony with the Skipton look-back, I think as a consultant I often reflect on being a cul-de-sac and I think a lot of challenges and problems and the weights of people will come to me. And some of it is very difficult to share and I think that the need to fix is always so high as a doctor and there's quite a bit of this that I cannot fix; I can make better but I can't rub out what has gone before.

I remember everybody. I may not have met them all. Some of my older men who aren't with us now who have told me as a junior doctor and told me stories of all of these amazing people and that they watched them die and what they died of. But I think my older men were very clever because they knew they were going to forget and in some way telling me -- you know, these men I say their names with pride. I am so proud of them. They did nothing, nothing, to warrant what happened. And yet, you know, families have been so affected. They have lived many years of not telling anybody what happened to them as if it's a little secret that they can't get out, and that's eaten away at people to think that they can't share what happened. It wasn't their fault that they got HIV. They didn't deserve to get HIV. They didn't deserve

to die of AIDS. But they did.

And I stand on the history of the service and remember them and every time you inject recombinant factor, you remember why you inject it. You remember why such lengths were gone through in order to get it. You can't unforget and I'm glad that I can't forget. Every time there's an empty seat in the waiting room I think that could have been him and I could have had an opportunity to look after but I didn't.

So, yes, I think my career has changed from what little green consultant in 2008 thought I could save the world and, you know, all I can ever do is try to improve on what has gone before. That's how I've always strived.

MS FRASER BUTLIN: I have no further questions, Dr Benson. We do need to take a short break so that the recognised legal representatives of Core Participants can tell us if they have any further questions.

Sir, I imagine you may have some questions as well.

SIR BRIAN LANGSTAFF: I just have two or three but I will wait, obviously, until you have garnered whatever questions there may be and any questions, of course, from those who represent Mr Benson too.

MS FRASER BUTLIN: Indeed.

SIR BRIAN LANGSTAFF: Let's say half-an-hour. Would that be long enough, do you think?

MS FRASER BUTLIN: I expect so, sir.

SIR BRIAN LANGSTAFF: Does that give you enough time to have a proper break?

A. Yes, thank you.

SIR BRIAN LANGSTAFF: Okay, half an hour and we will come back -- we'll make it 1.40.

(1.08 pm)

(A short break)

(1.46 pm)

SIR BRIAN LANGSTAFF: I'm sorry, Dr Benson, for a moment I thought we had lost you.

MS FRASER BUTLIN: Sir, I just have one question that has been passed on to me to ask.

Dr Benson, given your particular experiences and the particular perspective you have shared today, are there any suggestions you have of recommendations that the Inquiry should consider?

A. Good question. I think that it's certainly something that we've been involved with both within the centre and have reflected that back to decision-makers locally. I think the one thing that -- having met with all families -- well, most families -- and having been touched by their lived experience with regards to

the infections, I think that it's not just wives or spouses that have been particularly affected. I have met many parents who have lived life with regards to their sons not being with them anymore and having died from infection. And I think sometimes whenever we look at those lives affected, I do think that additional consideration should be given towards parents. You know, they have lived with the fact that whenever their sons were much younger, was it that one infection -- was that one injection that they had given to their son, was it that one injection that they had said, "Look, come on, you are meant to take this, go on", and encouraged them to take it?

So I think parents are -- many are not with us anymore, but I do think that their particular highlight -- have been highlighted to me, and I would agree.

The other group then are really the lost experience of the children for these men. I get to meet these young women and young men with regards to their own children that will come into the centre with their bleeding disorder, and I can see lives, opportunities that have been lost over the years of not having a second parent in order to provide that support or that emotional support to them. You know,

school holidays that can't be afforded, houses that have to be changed, but more so with regards to the parents and the children and the inability of being able to explain to their friends of what actually their fathers had died of and retaining that information.

So I think for me with the Inquiry, all the advances and changes in the recent weeks with regards to spouses and widows is exceptional and very welcome as a start, but I do feel and I do see the impact on parents as well as children.

MS FRASER BUTLIN: Sir, we've not --

SIR BRIAN LANGSTAFF: Sorry, is that the --

MS FRASER BUTLIN: That was the last matter from the recognised legal representatives. We haven't had anything directly from Dr Benson's representative. I'm not sure if they have anything they wish to raise.

Questions by SIR BRIAN LANGSTAFF

SIR BRIAN LANGSTAFF: I hope they are not subject to the same IT problems that we have been subject to.

When you said at an early stage in your evidence this morning that it was really quite telling -- this is in respect of the questionnaire -- really quite telling from the patients' perspective of how care had been, what did you see reflected to you

as to how care had been?

A. Yes, I think with regards to -- I suppose it's the long-term projection. So if somebody comes in with a bleed and that bleed is effectively managed and the patients are supported through it, but I think the direction of -- you know, I often reflect with the patients that today's decision is tomorrow's revision. So what I decide with them today is something that maybe 5/10 years' time I'm going to have to revise with them. So whilst we might solve the problem today by replacing a knee or a hip or an elbow, you know, we have to remember in ten years' time we're going to have to go back in again and to do it.

So I think that the fact that there's a plan and there's a direction and there's something to support them as they go through it, that there's a point strung between hospital appointments, is what I have taken from it.

SIR BRIAN LANGSTAFF: Thank you.

You were asked about the medical model of care, the expression used in the audit, and as to what you might understand by that. You couldn't really fathom what was quite in the mind of the author. Indeed, you are absolutely right, I think, that we have to go to the author to know precisely.

But do you think it might be that he was thinking about the medical approach, i.e. treating the disease or the condition as opposed to taking an holistic approach, looking at the whole person in their social environment, their familial environment, their work environment as well as the hospital treatment, and finding out what their wants, their desires, their needs were, their values?

A. Yes, it certainly would be one of the takes, I think, on it and certainly the cornerstone with regards my own personal practice in looking after the patients from the outset. It's not just -- you know, I think that my *(unclear)* will teach medical students as they come in contact with any patient is that they are a person, first of all, and don't classify somebody based on a disorder that they have. I think sometimes people or patients with bleeding disorders, you know, very often "Have you had a bleed, have you taken your treatment?" and we really look at the disorder itself. I think stepping back and asking to talk to him or her about how their day has been and how their week has been and to understand how they live with their disorder, I think is much more telling and I think then that the support that they can get can be much more specific and they can actually see the support.

SIR BRIAN LANGSTAFF: You described how at the age of 13 to 14, youngsters -- you might call them very young adolescents or perhaps you might reserve the "adolescent" word for those above 13 -- they would transfer to the adult hospital. Now, while children, they might have the benefit of paediatric psychiatry, psychology support, while adults, they may have the adult version, what is there to cover the adolescent psychiatry which we've heard from others has been so important?

A. So whilst it's from that age it doesn't mean that there's a very clear cut-off from that provided(?) that they do come across. They do try to have an element of both physical and emotional maturity, I think, with regards to them arriving within an adult-based service. Our social worker works very closely with them and with families and we're aware of the teenagers or CAMHS-type psychology approach, which is largely delivered through the community for those patients or young men who may have that type of a, you know, need for an emotional support-type mechanism. So within Northern Ireland there is that teenager bespoke type of a service and also extends into the family as well. So for those with regards to access to it, it's not that they leave the paediatric service

and suddenly go into a chasm of nothing with regards to those types of agencies.

SIR BRIAN LANGSTAFF: Thank you. The last question, really, poses a scenario and I want to know what your impression is used to happen and what now happens, so far as you know about what used to happen and as far as you do know what does happen. Suppose that somebody who is suffering or has the condition of haemophilia A or B but is controlling it with prophylaxis is involved in, let's say, a road traffic accident, something of that sort, but they are not anywhere near Belfast they might be in part of South Tyrone or up around Omagh or the west, approaching the border. They presumably, if the injury was serious and required emergency treatment, be taken to the nearest Accident and Emergency unit, which would not be in Belfast, would it?

A. Yes, that's correct. We have had several instances of that over the years with regards to patients. In an emergency the Ambulance Service appropriately will take them to the nearest service with an Accident and Emergency Department to stabilise and look after the patient --

SIR BRIAN LANGSTAFF: So just tell me what happens with their clotting. Was it the case in the old days, if

I can call it that, that the doctor not being necessarily a haematologist himself or having ready access to haematological input would reach into his shelf and bring out a vial of Factor VIII concentrate and administer it? Would that be what would happen or what?

A. I suppose from my perspective with regards to where clotting factor concentrates are stored there within the Belfast City Hospital and Royal Victoria Hospital and concentrated within the Altnagelvin Hospital for the north west, historically whenever we would have sent factor to the local hospital's blood bank for patients to collect, on occasions where we have faced such issues with regard to road traffic accidents, we are aware of what stock currently being held pending its collection by a patient, therefore we will take the vials out of that bag and then we will use that for the patient.

Patients will carry a card which will highlight their bleeding disorder and treatment. The vast majority we have actually been phoned in advance and we have been able to despatch factor promptly and, on most occasions, the factor has arrived before the patient has in the ambulance. So, with regards to our perspective, that's where it's been. Historically,

I'm not sure whether or not all hospitals had historically stocked one or two batches of a clotting factor concentrate or whether or not, similarly, they were confined to sort of a hub and spoke type model, if they were confined to the hub. Of that, I'm less sure whether or not everybody held a little bit.

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

MS FRASER BUTLIN: Dr Benson's representatives confirm that they have no questions. Dr Benson is there anything else you would like to add?

A. Yes. So just briefly, I think, the haemophilia multi-professional team are a collection of healthcare professionals with a drive and a passion for their chosen discipline, as well as the patients that we get to look after. Over the last years, in direct response to patients and their families' needs, the expansion of this team has been supported by specialty commissioning service at the Health Board level and within the Belfast Trust, not just in meeting the needs or the cost of clotting factor concentrate but also in furthering the holistic care of the individual. Whilst none of the team had been present at the beginning for many of these patients' journeys, we have all walked along side them. At times we have

carried them and we will never forget the patients and their families.

We do hope that in doing so that we can ease the challenges that come along with living with a bleeding disorder in Northern Ireland. We have been, we are and we remain fully committed to continuing to enhance that support during and beyond the terms of the Inquiry, and at all times we do uphold the aims of the Inquiry with our 110 per cent support to it and our patients. Thanks.

SIR BRIAN LANGSTAFF: Thank you very much indeed for the energetic enthusiasm which you've shown throughout your evidence for the service of which you are part. For me I think, if I may say so, what sums up a lot of your evidence and approach were two things that you said, one towards the beginning, when you said you were not there to focus on our needs or what we think best for them but on their needs, talking about the patients that you served. And just at the end, when you were describing how you wanted to treat patients as a person. And indeed, I think what you were reading from a moment ago was scripted in advance, and you used the word "holistic" looking -- exactly the word that I had put in your mouth a moment or two before.

So these things don't go unnoticed. I don't think anyone would have failed to be moved by your reaction to some of the patients and be assured by that, as I see it, your care for your patients is deeply genuine. Nobody has questioned it, nobody could here after your evidence, and thank you very much for telling us what it is like now in Belfast and -- through Belfast, Northern Ireland.

A. Thank you.

SIR BRIAN LANGSTAFF: I just want to say a word or two to those who are watching. Easter is a time to look forward. We've come to the end of the current batch of hearing days. As most of you will know, we are about to take a break from hearings for six weeks. I want to take this opportunity to let you know of our plans for what happens after that.

You will understand that it cannot be absolutely cast in stone, for we are timetabling in what is still an age of uncertainties. But, first, those next six weeks will be well spent. We'll look at the questioning over the last few months and at the presentations. The evidence of the very considerable hard work done by my team and by counsel to the Inquiry has been there for all to see.

But I do not mean to suggest it's been down to

them alone. I'd like to pay tribute to the contribution that so many of you, directly or through your representatives, have made to the process. The label "Participant" says it all. The Inquiry depends upon all its participants for its success.

You have passed on the benefits of your own research, your own insights, your own questions. There's a lot more work to be done but it is being done, and it will continue to be done with your help. Thank you.

The fruits of that work over this coming break should be there to be seen in the future hearings, so what about those future plans? Well, in May the Inquiry will take evidence on financial support in all four UK nations about The Haemophilia Society, and it will consider the ethical and professional guidance which was given to clinicians.

In June, we will hear from campaigners who in the main have not previously given evidence, consider evidence about smaller haemophilia centres, and turn a spotlight on Lord Mayor Treloar's College.

In July, the first Government witnesses will be called to give evidence. Then we take a break from hearings, though work of course will continue, and during that pause in August the Inquiry will move to

its new premises on Aldwych. They will provide all of us with very similar facilities to those we have here. After that, hearings will resume from 20 September. So a break from the end of July to 20 September.

As I've said before, this autumn we will scrutinise the pharmaceutical companies and blood services. We will then hear from more Government witnesses, including on the issues of candour, openness and cover up. And, of course, more from those people who were infected and affected as a result of NHS treatment. I shall not forget my promise to put people first and last in this Inquiry.

The last thing I want to do is to impose further demands on those of you who felt they had to spend a lot of their available time, almost equivalent of a full-time job, watching the Inquiry hearings, reading disclosed materials in advance of them, and often suggesting helpful lines of questioning to the Inquiry through your representatives. I want to thank you again for that. It may seem to some of you that the pace at which we have had to move, despite the breaks, has been inexorable. But not only that. Some of the memories that the evidence has brought back to the surface may have been difficult and I just want you to know that I recognise that.

Right back at the start of the Inquiry I also set out the principle that we would complete the Inquiry as quickly as reasonable thoroughness permits. We must make best use of time, demanding though that is. I am therefore issuing today a statement of approach on final submissions now and encouraging those of you who are recognised legal representatives and unrepresented Core Participants to start -- not complete, how could you, but start -- yes, you can -- your preparations now for making closing statements, covering both the conclusions you think I should reach and those recommendations you hope I will feel able to make. I will read and hear those submissions when we come to the end of the oral hearings we have planned.

Well, for now, though, it is an Easter break. We have had a taste of fine weather already. There should be more to come. I hope you have had a chance to enjoy it safely and have a chance to enjoy what comes safely but, now that restrictions are easing, perhaps meet some of those you have not been able to meet for the best part of a year.

I wish you all a refreshing break.

(2.06 pm)

(Hearings adjourned until week commencing 17 May 2021)

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