Thursday, 10 June 2021

(10.00 am)

SIR BRIAN LANGSTAFF: Now I think you may have been saying something there, Simon.

MR HAMILTON: Good morning, Sir Brian.

SIR BRIAN LANGSTAFF: Good morning.

MR HAMILTON: Yes, I was just having a chat with the technician.

SIR BRIAN LANGSTAFF: So you're at home, are you?

MR HAMILTON: I'm not, no, I'm out in our business office. The company very kindly gave me access here to our boardroom because we have a particularly good signal and I didn't want to risk the quality of what we were going to be doing by working from home, as it were, because I live quite rurally and we have an agricultural connection in terms of our technology.

SIR BRIAN LANGSTAFF: Understood.

MR HAMILTON: Thank you.

SIR BRIAN LANGSTAFF: You're joined this morning by Lynne Kelly and Bill Wright, if you'd come forward please.

Now you need no introduction to each other, I think. But let me just tell you, Simon, you're talking to what is for us a full house. I'd say for us, in the present circumstances.

MR HAMILTON: Yes.

SIR BRIAN LANGSTAFF: But beyond this room there will be quite a lot of the people watching today. We are expecting 200 or 300 at least from the various constituent parts of the United Kingdom.

MR HAMILTON: Yes.

SIR BRIAN LANGSTAFF: So that's who you're talking to.

MR HAMILTON: Thank you.

SIR BRIAN LANGSTAFF: Now we'll take the -- administer the oath. You first, Simon. Mary will administer that in a moment. Mary, please.

SIMON HAMILTON, affirmed

LYNNE KELLY, sworn

WILLIAM WRIGHT, affirmed

SIR BRIAN LANGSTAFF: Let me just check that you have a screen in front of you. Can you see Simon in that screen? You can. Good. Then that part of it is working. Can I just mention now, for later, that you are a panel. If you are to have discussions between yourselves, they should be in public, so the usual -- today, that is. Afterwards, you can talk as much as you wish in private. So during breaks if you please, don't talk about the evidence that you've been giving and that which you might be asked to give.

It's the usual rule for everyone adjusted for

circumstances of a panel. If you find that you don't agree and want to say something, this is the forum to say it. We do want to understand the differences between the different constituent parts of the United Kingdom insofar as they are important to us.

Questions by MS FRASER BUTLIN

MS FRASER BUTLIN: Simon, before I start, can I make sure you can see and hear me?

MR HAMILTON: I can, yes, thank you.

MS FRASER BUTLIN: I'm not sure when I look at you whether you feel I am looking at you or not because of the way my screens are set up but please don't think I'm being rude if it looks like I'm looking away from you.

MR HAMILTON: No, no, I totally accept that, thank you.

MS FRASER BUTLIN: Before we start with the evidence, sir, I do need to highlight that it's inevitable that some criticisms are likely to be made by these witnesses of various individuals and organisations. As we said yesterday, through no fault of their own, several of those people may not have had the opportunity to respond to those criticisms, as yet. But as and when responses are received, they will be published on the website. In some circumstances we do have a response, and I'll note those as we go, but no inferences should be drawn from a lack of response.

SIR BRIAN LANGSTAFF: Thank you.

MS FRASER BUTLIN: Simon, if I can start with you. You've been the chair of Haemophilia Northern Ireland since it was founded in December 2017.

MR HAMILTON: Yes, that's correct.

MS FRASER BUTLIN: There was previously a Northern Irish group of The Haemophilia Society.

MR HAMILTON: Yes.

MS FRASER BUTLIN: Can you tell us why Haemophilia Northern Ireland was formed?

MR HAMILTON: Yes. As far as I understand there has always been a local branch of the UK Society. Due to a period of inactivity and, therefore, a sense that there was a lack of representation, it was felt that, in light of the model, if you like, that was in Scotland and Wales, that it was perhaps time that a local charity in its own standing would be formed, replicating what was being carried out elsewhere. And the desire to better advocate for people in Northern Ireland who were suffering from blood issues, we felt that it would be useful to form a society because there had been a period of inactivity, fundamentally, and, as a consequence of that, we felt that representation could best be served by a local group, a local group setting itself up as a recognised

charity, a Northern Ireland Haemophilia Society.
MS FRASER BUTLIN: Can you tell us what the aims and objectives of Haemophilia Northern Ireland are?
MR HAMILTON: Yes, fundamentally we see ourselves as advocates and supporters of all haemophiliacs, bleeding sufferers, von Willebrand's sufferers, et cetera. We set ourselves up regardless of the issues relating to the public Inquiry. That wasn't a driver for us setting ourselves up. Fundamentally we set ourselves up in order to provide support and a talking shop somewhere, where counselling guidance, as it were, signposting could be provided and the normal charitable activities to support different groups relating to the bleeding disorders. So young parents, families, children, young adults, older men, von Willebrand's sufferers and -- issues relating to women's bleeding disorders and, in general, to be a voice in Northern Ireland, because we observed in other regions that there was an effective voice when individuals took up, if you like, an indigenous charitable role, and ran with those objectives.

And those were fundamentally our objectives: to provide support and advocacy for families and sufferers, the infected and affected, the affected with this -- with the blood disorder.

However, because of the timing, we also felt that it was important to represent issues relating to the public Inquiry and the infected blood scandal, and because some of us were obviously in the category of being recipient -- scheme recipients, we were already recognised sufferers from the infected blood and therefore we formed part of that victim group. And under those circumstances it made total sense that we would provide a voice for people in Northern Ireland who wanted us to -- who wanted to channel their views through us. And as a consequence, then, another stream of what we try -- have tried to do was to provide representation and to be an active voice, advocating for the needs of people who fall under the infected blood scandal.
MS FRASER BUTLIN: You gave evidence when we were in -- when the Inquiry was in Belfast, so your personal story has been provided to the Inquiry.
MR HAMILTON: Yes.
MS FRASER BUTLIN: But it's right, isn't it, that you were involved in campaigning around some of the issues on financial recompense prior to the formation of Haemophilia Northern Ireland?
MR HAMILTON: Yes, my involvement in --
MS FRASER BUTLIN: We'll come to the detail of that in

a moment but just to confirm that you were certainly involved prior to the formation?
MR HAMILTON: Certainly, I was. Yes, that's correct.
MS FRASER BUTLIN: Bill, you've been an active campaigner in Scotland over a number of years. I know you're not a fan of the word "campaigner", but if we can use that term in terms of -- you've had an active involvement in a lot of the issues in Scotland, starting off in about 1997, 1998?
MR WRIGHT: Yes.
MS FRASER BUTLIN: And that was as a member of the Scottish Haemophilia Groups Forum?
MR WRIGHT: Yes, both individually, in terms of writing to politicians and ministers, but also a bit of a guy in the background within the Scottish Haemophilia Groups Forum.
MS FRASER BUTLIN: In terms of the Scottish Haemophilia Groups Forum, that drew on representatives from The Haemophilia Society local groups in Scotland?
MR WRIGHT: That's correct.
MS FRASER BUTLIN: Can you tell us in 2010 how the Scottish management committee of the Scottish Haemophilia Society came to be established?
MR WRIGHT: Well, at that time, the Society had appointed a very dynamic Scottish officer. Can I name her?

MS FRASER BUTLIN: I believe so. I don't believe she's anonymised.
MR WRIGHT: Susan, who brought a great deal of expertise and energy to Scotland -- *[Redacted]*
MS FRASER BUTLIN: Could we pause the transmission?
SIR BRIAN LANGSTAFF: Yes, you might have mentioned this, actually.
MS FRASER BUTLIN: Can I take a moment?
SIR BRIAN LANGSTAFF: I think leave those details, leave those personal details out. Can we just redact that for a moment, sorry.
MR WRIGHT: Sorry, sir.
SIR BRIAN LANGSTAFF: It's just protecting -- it's fine to mention her name.
MR WRIGHT: Yeah, okay. Um, Susan was a very dynamic, very bright, intelligent -- brought a lot of energy.
MS FRASER BUTLIN: Just pause a minute. I just want to make sure that the transmission.
SIR BRIAN LANGSTAFF: I think it's on again. We're okay. Yes.
MR WRIGHT: She had experience of bleeding disorders. She was very bright, energetic, and renewed a lot of the energy within Scotland, and she kind of got me hooked in to all of this. I physically had a collapse following my fourth attempt at interferon treatment in

2007, and my wife was reluctant for me to get involved at all. However, Susan dragged me along to a couple of meetings, and that led to a very -- a renewed involvement in the whole affair.

MS FRASER BUTLIN: There was a governance review by the UK Haemophilia Society which resulted in the Scottish Management Committee being established?

MR WRIGHT: Yes.

MS FRASER BUTLIN: In about 2010?

MR WRIGHT: Yes.

MS FRASER BUTLIN: And in 2011 you became chair of that committee, is that right?

MR WRIGHT: Yes, the committee had struggled because frankly a lot of people became ill, and I was approached by the then chair of the UK society to form a Scottish committee, completely undemocratic, but I went about that task. Between us, Susan and I recruited a few people to join that committee. It was our intention that we -- we made ourselves democratic. And initially our focus was very much on the issues that Simon's talking about, about people with bleeding disorders, families, and so on and so forth, who -- we actually wanted to highlight the understanding of bleeding disorders in haemophilia in Scotland, and we ran some events in the Scottish

Parliament to that fact.

So I -- there was already a sort of steering group, briefing group for Thompsons Solicitors, who had been drawn from campaigners across Scotland, and therefore at that point we weren't particularly involved in the Penrose Inquiry. I, in an individual capacity, was a Core Participant of that Inquiry quite actively, but I didn't at that point -- I was -- I thought it was important to allow the steering group to be the main people briefing the -- Thompsons Solicitors.

MS FRASER BUTLIN: We're going to come back to lots of that detail.

MR WRIGHT: Of course.

MS FRASER BUTLIN: If we could just map out your involvement.

MR WRIGHT: Yes.

MS FRASER BUTLIN: 2011, you were chair of the management committee. And then, in 2012, the -- Haemophilia Scotland was established as an entirely separate entity.

MR WRIGHT: That's correct.

MS FRASER BUTLIN: My understanding is that, for a long time, the Scottish part of The Haemophilia Society had, in reality, been quite separate to the rest of

the society but just very broadly, can you tell us how Haemophilia Scotland came to be established?

MR WRIGHT: Well, in many senses it was the Penrose Inquiry that led to that, because we reached a point where, as Lynne might cover, I think you might have been a trustee at the time in 2012, there were very understandable calls for a UK inquiry, and we found ourselves in a position where we were amid a very big inquiry, one of the biggest inquiries that's taken place in Scotland, and so our view was that we simply couldn't engage in that process at that point. And so we also looked at the terms of the 2005 Inquiries Act, which I think section 24 talks about, devolved governments' involvement in UK inquiries, and we took some advice about this because, politically, we thought it would be nigh on impossible.

Scottish Government was spending £12 million on its own Inquiry, and we really couldn't see how it would engage in the way that it needed to, in the way that it's now engaged in this Inquiry, and actually act on the recommendations of this Inquiry, when there may be conflicting recommendations came from Lord Penrose's Inquiry.

So that was really one of the main reasons. But I've presented a document that -- it was presented

actually at a meeting of the Scottish Haemophilia Groups Forum in my own front room in our house, where, when devolution took place in 1999 in Scotland, one of the members of that committee at that point said we need an independent charity in Scotland. And it took us, in effect, 12, 13 years to go through that process and finally do it. And, I have to say, when we made that decision to effectively break away, my wife was not a happy woman, because we had no money, we had no staff, we had no constitution, we had no charitable status. All we had was a hell of a lot of goodwill from people in Scotland. Bruce gave us his goodwill. We had the goodwill of the Haemophilia Centres in Scotland as well and the Scottish Government, ministers, in effect, welcomed the step we were taking.

So I cannot emphasise enough the importance of devolution in this whole story, as I hope I'm able to illustrate as the day goes on, but that -- those moments when we broke away, we got nothing other than goodwill and hard work and, later, we hopefully were able to make an impact.

MS FRASER BUTLIN: Can you just outline for us the aims and objectives of Haemophilia Scotland?

MR WRIGHT: Yes, they're set out in our constitution, in

our governance documents, which are registered with the office of Scottish Charities Regulator, OSCR. In summary, they are very similar to Simon's. They involve providing information, they involve support for people with bleeding disorders, and they involve advocacy.

MS FRASER BUTLIN: I will try and use the term "advocacy" rather than "campaigning" for you, Bill.

Lynne, as I've indicated we've heard evidence from both Bill and Simon in previous hearings about their own personal story. Can you tell us a little of how you came to be involved in campaigning in Wales?

MS KELLY: Okay. So my involvement started when my first son was born with haemophilia in 1989. My grandfather was a haemophiliac and there were three generations of haemophilia in my family, so I already had four cousins with haemophilia. I wasn't involved with the early campaign at that point, but I was involved with the South Wales Haemophilia Group, and I did mainly the activities with children, supporting children's activities and family's needs and mother's meetings and raising money.

But my campaigning started with regard to recombinant Factor VIII and that was the first time that I'd contacted MPs and that was when I met Julie

Morgan, who was my MP at the time, at Westminster, along with other mothers in her constituency and we were basically looking for non-plasma derived Factor VIII.

So we met Julie and she lobbied on our behalf and we managed to get recombinant Factor VIII by the time my third son was born with haemophilia in 1997/98. So that was the start of my campaigning. But then when devolution came in -- sorry, do you want me to carry on?

MS FRASER BUTLIN: Do, yes.

MS KELLY: When devolution came along in 1999, there had always been a difficult relationship with The Haemophilia Society and the South Wales Haemophilia Group because obviously, as a group, we felt we were raising money and the money was going up to London but we weren't seeing any benefit from that money. So there were various issues regarding fundraising and around the campaigning, which members of the South Wales Haemophilia Group, the main campaigners, who I think I can name as Paul Jenkins, and the Lewis brothers, but *[redacted]* but I won't mention anybody else.

MS FRASER BUTLIN: Can we pause the transmission?

[Transmission paused]

MS FRASER BUTLIN: The final name there needs to be redacted.

MS KELLY: Oh, I'm sorry.

MS FRASER BUTLIN: Are we live, again, sir?

SIR BRIAN LANGSTAFF: We are.

MS FRASER BUTLIN: Thank you. You were just saying there were some difficulties in relation to fundraising and around the campaigning.

MS KELLY: Yes. So basically we felt that in Wales we would do better to start lobbying the Welsh Assembly, which was established then in 1999, and we held the first Cross Party Group there in 2001, and that was led by Plaid Cymru, so we felt from an early start, then, we had a good relationship with the Welsh Assembly and many of the Welsh politicians, they got to know us. So obviously, things carried on with the campaign, very much from a Welsh perspective, and then Haemophilia Wales was established as a charity in 2003, and --

MS FRASER BUTLIN: After 2003, it was subsequently wound down --

MS KELLY: Yes.

MS FRASER BUTLIN: -- because people were unwell and unable to maintain it?

MS KELLY: Yes.

MS FRASER BUTLIN: Then I think it's right, isn't it, that you re-established the group in 2014?

MS KELLY: Yes, so by 2010, six of our committee members had died and as a mother with three boys with haemophilia I felt that I could bridge the gap between the needs of the newly diagnosed families and the needs of the infected blood community. But I decided that it would all be down to me, basically, to do all of that. So I thought it would be better to apply to be a trustee of The Haemophilia Society, which I did, and I was elected. So I joined The Haemophilia Society in 2011. But I did tender my resignation in 2014, because I just felt completely disillusioned with the way they were -- they weren't actively engaging in the campaign and there just was no urgency to address the very real issues in our community, particularly in Wales but across the wider UK.

MS FRASER BUTLIN: Out of that, the Haemophilia Wales was established?

MS KELLY: Yes.

MS FRASER BUTLIN: I should say at that point, sir, we've had a response from Bernard Manson in relation to some of the criticisms raised in Lynne's statement about The Haemophilia Society and it will be on the website and published in due course.

SIR BRIAN LANGSTAFF: Thank you.
MS FRASER BUTLIN: You've been the chair of Haemophilia Wales since 2014. Can you tell us also what the aims and objectives of Haemophilia Wales are?
MS KELLY: Okay. So we provide information, support and advocacy to people of all ages with inherited bleeding disorders in Wales, and to some outside of Wales as well. We also campaign and represent transfusion victims, and that has mainly come from our work with the Cross Party Group at the Welsh Assembly, because obviously there were Assembly members in the Welsh Parliament who had constituents who had been affected by contaminated blood but they weren't haemophiliacs. And our meetings at the Welsh Assembly were always quite large and people would come to meetings and basically when all the people got into room together and they started networking, we could see that the issues were the same.

So our group just grew and grew, and basically we have a united voice and we represent both haemophiliacs infected with contaminated blood but also transfusion victims, families and bereaved families.
MS FRASER BUTLIN: You've also been heavily involved in the Cross Party Group on haemophilia and contaminated

blood since 2011.
MS KELLY: Yes.
MS FRASER BUTLIN: Who makes up that group?
MS KELLY: So initially Julie Morgan, who was my MP at Westminster, she became an Assembly member or, as they are now known, members of the Senedd in the Welsh Parliament, in 2010. And, obviously, I met with Julie and -- well, she actually thought it would be a good idea if we had a Cross Party Group and because she knew there was a lot of cross party support for our issues. She understood the concerns, she knew lots of the families anyway.

So the Cross Party Group was established. Julie is no longer chair because she was promoted to Deputy Health Minister in 2019. So the chair was Mick Antoniw, but we've just had another election and we're in the process of electing another chair for the group. But basically, heavily involved in that, and our meetings are open to anybody who has been, you know, affected or infected with contaminated blood or, indeed, if they have any issues relating to haemophilia and those issues aren't being resolved through our All-Wales Advisory Group on Inherited Bleeding Disorders, they can bring those issues to our meetings as well. And our meetings are very large,

anybody can speak out, and they can say -- they can talk about the issues that they would like to be raised, and they feel that it's a safe environment to do that.
MS FRASER BUTLIN: I want to go back in time to May 1999, Bill, with you, when the Scottish Parliament was formed, and the advocacy work that was done at that stage. One of the first things that was done was that the Scottish Infected Blood Forum submitted a formal petition, PE45.

Could we have that on the screen, please, Soumik. It's WITN2287022. Next page, please.

We can see there that it's a petition to the Scottish Parliament calling on the Scottish Parliament to:

"... hold an independent inquiry into hepatitis C and other infections of people with haemophilia contracted from contaminated blood products in Scotland and to consider providing financial assistance for people with haemophilia affected by HCV similar to that already provided with people with haemophilia infected with HIV."

Bill, how did this petition come to be submitted?
MR WRIGHT: Well, I was heavily involved in this. In my

working life, I worked in the third sector. I worked for an environmental charity that was campaigning for the -- campaigning for the Cairngorms to become a National Park. And within that, I was very involved with an umbrella body called Scottish Environment Link. In fact, a lot of the thinking that went into the whole idea of having a petitions committee within the new Parliament had been -- had come up via the Scottish Civic Forum, which was the body that designed the Scottish Parliament, and Link had been feeding into that idea and seeing what needed to happen.

So I was very aware of the opportunity that the petitions committee presented. We'd had complete intransigence within Westminster. We were getting nowhere in London. Philip Dolan, who was -- the late Philip Dolan, who was incredibly energetic, for a man of some age, was travelling up and down to London, something, I have to say, until this Inquiry I have avoided, but he was trying very hard to get some movement. We were writing to MPs and our voice was not being heard.

So this petition in many ways was absolutely pivotal to what happened next in Scotland, because there were discussions about what had happened to us. People were dying at that point, already dying. And

people were in very ill health, we were starting to learn that the damage that hepatitis C was causing, and the Scottish Haemophilia Groups Forum at that point -- again, I think it might have been a meeting in my front room -- said, "We need to go there", and you'll see it's PE45. That's one of the earliest petitions to be submitted within the Parliament.

I had experience because I was also presenting petitions about the Cairngorms. So we went down this line. It was a real opportunity, the proposal went to the petitions committee. The only real condition on getting that in front of the Petitions Committee, was that we'd already spoken to Scottish Government about the idea of an inquiry. Susan Deacon was then the Health Minister and she was saying no, an absolute no.

And so we thought well, we're not giving up on this. Let's take this to the Parliament, and we were welcomed with open arms by that Petitions Committee who then quite correctly passed on the proposal to the Scottish Parliament's Health Committee, and that was extremely significant because we gave evidence to that committee in Parliament, and there were some very significant figures at that time on the Health Committee.

MS FRASER BUTLIN: We're going to come to the Health

Committee in just a moment, Bill, but just in terms of this petition, this was submitted, a separate petition was submitted by someone else calling for a compensation scheme for those who'd contracted hepatitis C from blood transfusions and the two petitions went forward together, didn't they?

MR WRIGHT: That's correct.

MS FRASER BUTLIN: You mentioned a moment ago your interactions with Susan Deacon and whether there should be an independent inquiry. Just prior to these petitions, there had been discussions, hadn't there, between The Haemophilia Society and Susan Deacon about a departmental inquiry?

MR WRIGHT: Indeed. Can I just point out, you used the word "your". I have never met Susan Deacon, even though I wrote to her asking to meet her. She refused me.

MS FRASER BUTLIN: These petitions were held while the internal departmental inquiry took place, weren't they?

MR WRIGHT: Yes.

MS FRASER BUTLIN: But you had quite considerable concerns about that departmental inquiry, didn't you?

MR WRIGHT: Well, it was civil servants looking at themselves, marking their own homework.

MS FRASER BUTLIN: We've got a letter you wrote and if we could put that up on the screen, WITN2287024, page 2 -- I'm sorry, it's the next page, Soumik. We can see in the third paragraph that this is your letter to Susan Deacon. You said:

"Simply to undertake to publish the findings of a departmental enquiry doesn't give rise to confidence in open government when a departmental enquiry may well involve officials who have in the past been involved in either 'advising' on matters they themselves are being asked to investigate. They are potentially being asked to either criticise themselves or other public servants whom they have worked closely with."

Then the bottom of the letter:

"Given the potential controversy brewing over this affair, I urge you not to leave this matter in the hands of your department or the Scottish National Blood Transfusion Service to deal with, but to take a hands on approach to ensuring that an investigation is wide ranging, open and thorough."

They were your concerns about the internal departmental inquiry?

MR WRIGHT: That's correct.

MS FRASER BUTLIN: In her reply, she simply said that

those points would be considered, didn't she?

MR WRIGHT: Yes. I think it's worth bearing in mind that when the Scottish Parliament was formed, and therefore a Scottish Government, there were two dynamics happening. First of all, we had got a fresh new Parliament. The majority of MSPs had never been Parliamentarians before. They were new, enthusiastic, they wanted to get stuck in and, as we'll see in terms of the opposition MSPs at that point, they really got stuck in. But you don't just magic the other part of government, the Civil Service, out of nowhere. Effectively, we still had the same behemoth that was the Scottish Office civil servant who got -- all got similar positions within the new -- it was actually called the Scottish Executive at the time. And that's what I think particularly alarmed us at that time.

MS FRASER BUTLIN: In the interests of fairness, the response from the Scottish Executive was that they had made clear to you that they would be open to scrutiny conducted in an impartial manner but, from your response, you were not convinced that that would be --

MR WRIGHT: I contest that.

MS FRASER BUTLIN: The report of the departmental inquiry was published in October 2000 and we've got a copy of the full report but what I want to take you to is the

letter that you were sent, which copies across the conclusions and makes some other points that we want to look at as well. It's WITN2287025, please, Soumik. If we pick up at page 3.

No, sorry, back one page. Thank you.

We can see there the heading "Findings" and these are copied across from the report of the inquiry, the departmental inquiry. The findings were:

"the Scottish National Blood Transfusion Service were around 18 months behind the Bio Products Laboratory in England in producing a heat-treated product which was subsequently found to have eliminated the hepatitis C virus;

"there were understandable technical reasons why this was the case:

"there was no test to identify the presence of the virus, so scientists could not be sure that any particular heat treatment had actually worked until they reviewed the effects of the resultant products on patients;

"the heating process could easily render blood products unusable, and different types of heating and freeze-drying processes and equipment had to be tried in order to obtain a usable product;

"once SNBTS had managed to develop a suitable

heat-treated product, they were quickly able to produce sufficient for domestic demand;

"no evidence of any policy by Haemophilia Centre Directors deliberately to mislead patients about the risks of hepatitis."

Bill, what was your reaction to this report?

MR WRIGHT: Well, I'd had one of these -- these products. As I've given evidence personally, from a single dose, in 1986, I was infected with hepatitis C, leading to four attempts at interferon treatment. It was a pretty pathetic attempt at getting to the truth and certainly the subsequent evidence that's come about through this Inquiry so far, and indeed the Penrose Inquiry, actually shows how wrong they were.

MS FRASER BUTLIN: Soumik, could we have the letter that went to Bill, WITN2287026.

We can see there the bullet points that I've just read from the report, and then the last paragraph on the first page:

"The Minister considers it an important general principle that the NHS should not pay compensation for non-negligent harm; she acknowledges that medical treatment often necessarily involves a balance of risks. She would like to repeat her expressions of sympathy to haemophiliacs infected through blood

products, as indeed to all people who have suffered inadvertent harm through medical treatment.

"She also notes that the exercise failed to find evidence of any policy by Haemophilia Centre Directors deliberately to mislead patients about the risks of hepatitis. She cannot deal with individual cases where a patient believes he or she was nevertheless misled, although she sympathises with any patient who was unable for whatever reason to appreciate the risks of their treatment."

Again, what was your reaction to that part of her letter?

MR WRIGHT: Oh, god! Can we go back to the previous paragraph, please.

MS FRASER BUTLIN: The bottom of page 1.

MR WRIGHT: "... repeat her expressions of sympathy ..."

She was bloody patronising.

SIR BRIAN LANGSTAFF: Take a moment.

MR WRIGHT: I later found out just what was going on there. She wanted to take us to the courts.

Can we go to the next paragraph, please?

She didn't want to meet the requests of either PE45 or PE185.

Can we deal with this "deliberately" element? I'm here, sir, under oath to speak the truth, but also

the whole truth. Now, in terms of the whole truth that's coming to light during this Inquiry, I'll give an example of what happened to me personally.

Christopher Ludlam, who was my consultant -- you, sir, are in a better position than I to judge intent, so I don't know about the word "deliberately", however, what I will say is he did not tell me the whole story, when I was infected. It took me until the late 1990s to find out that there'd been an investigation into my infection. He didn't tell me that. So whether it was deliberate or not, he simply didn't -- she uses the term "deliberately". She didn't -- the doctors were not telling us the whole story at that time. She also says:

"She cannot deal with individual cases where a patient believes he or she was nevertheless misled ..."

No, because she wanted -- as will hopefully come out in evidence, from 15 years later, she wanted to point us at the courts, and fight us there.

MS FRASER BUTLIN: Let's pick that straight up.

If we can have WITN2287029.

If we go to page 3, this is a news article that you've exhibited to your statement which is headlined "Records reveal minister unease over blood scandal

payouts", published in January 2017.

And if we go over the page, we can see that the article says this:

"The newly-declassified papers from 2001 show the then Scottish Executive feared paying out up to £20m to people affected by the scandal."

A little further down:

"The documents released by the National Records of Scotland under the 15-year rule show ministers feared making payouts to 400 patients who received contaminated blood between the 1970s and 1991 because they thought it would create a precedent for compensation and lead to 'immense future difficulties'.

"Susan Deacon, health minister at the time, said defending the claims would mean the Executive would look 'unsympathetic' but said her 'inclination' was for court action because of the wider implications."

Bill, that's obviously something that you read about later than the letter from her.

MR WRIGHT: Yes.

MS FRASER BUTLIN: But can you tell us at this point: after this October 2000 letter from Susan Deacon, what was the stance taken by the Scottish Executive --

MR WRIGHT: Sorry, October 2000 and?

MS FRASER BUTLIN: October 2000 is the letter from Susan Deacon. From that point until -- for the next few years after that, what was the stance taken by the Scottish Executive towards your requests for an inquiry and recompense?

MR WRIGHT: Well, between 1999 and a pretty radical change in the political scene in Scotland in 2007, in terms of a different colour of administration, there were three ministers: Susan Deacon, Malcolm Chisholm and Andrew Kerr.

We have to acknowledge that Malcolm Chisholm, when he became minister, he did actually try and act on these petitions, and the process that was taking part in the Parliament, by ordering the investigation that was led by Lord Ross, and on which the late Frank Maguire of Thompsons Solicitors and the late Philip Dolan sat on, along with anonymous witness I think it was AA or X or whatever who had been infected. And he reported -- and there was -- we felt there was some really useful stuff in that. And subsequently, ten years later, when I was chair of Haemophilia Scotland, I talked to Dan Farthing, our chief executive -- we had got staff by then -- and said, "Look, it's ten years, this is a good punch point at which to look at what Lord Ross said", and

I presented an analysis of that --

MS FRASER BUTLIN: We're going to come to that.

MR WRIGHT: Okay. But Malcolm Chisholm -- and it appears that this is really what led to the establishing or was a big influence in the establishment of the Skipton Fund. What we struggled with was what was going on between Westminster and Edinburgh. John Reid was the minister at the time within the UK Government, and I've never really got to the bottom of why Lord Ross's recommendations were not implemented. And in fact, in terms of the Skipton Fund, the amounts were much less, and they were made UK-wide.

It's important, I think, that -- my understanding is that the money went to the -- in effect, the Skipton Fund acted as the administrative body for the payments from Scottish Government to those of us who'd been infected in Scotland.

So that was a significant factor but nevertheless I've never got to the bottom of what was going on between John Reid and Malcolm Chisholm, between the respective governments at that point. There is some evidence that takes us in that direction, but this Inquiry -- I would really welcome this Inquiry taking us to places I've never been able to get to in terms of Government documentation in that

respect.

MS FRASER BUTLIN: Before we get to Malcolm Chisholm's role, just staying with Susan Deacon, you had the letter saying there was not going to be any consideration of financial recompense. You also, in your statement, have recalled observing a debate from the public gallery at some point in 1999 and 2000, and I think this also ties in to your evidence about the issues with the civil service element of Scotland. What do you recall -- what can you tell us about that?

MR WRIGHT: Well, we're introducing a key figure in Scotland into the story.

Can I name them?

MS FRASER BUTLIN: I don't believe she's --

SIR BRIAN LANGSTAFF: Are they a public figure?

MR WRIGHT: A senior civil servant.

MS FRASER BUTLIN: I don't believe it's been redacted, sir. I'm just going to quadruple check.

It's not been redacted.

SIR BRIAN LANGSTAFF: Yes, you can.

MR WRIGHT: Dr Aileen Keel, who was the Deputy Chief Medical Officer of Scotland, had been heavily involved in this whole story. She'd been Deputy Chief Medical Officer prior to devolution, she remained Deputy Chief Medical Officer immediately after. I've had

a conversation with Bruce, and he has a similar recollection, that in the very, very early days of Parliament she somehow appeared at the front bench passing a piece of paper to the Health Minister, which I thought was a really weird thing to do.

I may not -- I may have misidentified her, however, she was involved in several meetings that I've presented in submissions, where she clearly had an involvement. She was involved in the meeting between the directors and the Scottish Government in February 2000 that we may come on to. She was involved in advice to ministers. If you look at the look-back exercise, she was -- that's discussed, she was the point of contact.

MS FRASER BUTLIN: We'll pick up her role later on.

MR WRIGHT: Okay.

MS FRASER BUTLIN: But just in terms of that time frame, of 1999 to 2000, your recollection of seeing her pass a note to -- or you think it was her passing a note to Susan Deacon during a debate, and you've said in your statement that that gave you some realisation of the impact of devolution and the difficulties that might -- you might be facing.

Can you tell us a little bit more about what you were thinking there.

MR WRIGHT: I think I -- that was the moment that it hit home that it was not just the elected Government that was in control here. There was a great deal of experience of the story, good and bad, within Scottish Government in terms of what used to be the Scottish Office. And one of the things that has intrigued me and concerned me throughout the story is actually prior to what's called devolution, my understanding was that there was already a considerable degree of devolution within the British Government to the Scottish Office.

And while there were very different colours politically north and south of the border -- in fact we had a moment where I think they were struggling to find a minister of the correct colour within the Scottish Office -- there was -- decisions were allowed to be made. We had a different legal system. Whenever you passed an act of Parliament, you had to have the Scotland Act. And so there was a Health Minister in the Scottish Office, Sam Galbraith, prior to 1999. He then became, in the new Scottish -- he was one of the guys, in a sense, who was the baggage from pre-devolution as a politician, the late Sam Galbraith, who was a surgeon by profession, but he then took a cabinet post post-devolution, as Education

Minister if my recollection serves me correct.

So I'd really like the Inquiry to get to the bottom of -- we were a bit naive, I think, at times where the Scottish -- in terms of the importance of the Scottish Office in this whole story.

MS FRASER BUTLIN: After the departmental report, the Inquiry report was published, as you said, you then gave evidence to the Health Committee in March 2001?

MR WRIGHT: That's correct.

MS FRASER BUTLIN: And we've got the conclusions of the committee, if we can look at that.

WITN2287028, please. And I think it's page 20 that we want. Sorry, it's page 21. Thank you.

We can see the heading "Conclusions", and I want to pick it up in paragraphs 97 and 98:

"We are not persuaded of the case for a further, independent inquiry into all the concerns raised by the Haemophilia Society and others, if that were to focus mainly on exploring questions of alleged fault. The evidence we have so far considered does not suggest that this is likely to be a fruitful line of Inquiry. We are also concerned that further investigating issues of fault would only delay consideration of whether and how financial and practical assistance could be provided to sufferers.

A review of the adequacy of clinical advice on risks arising from blood and blood products would, however, be welcome."

Then paragraph 98:

"We have come to the view that financial and other practical assistance, awarded on a no-fault basis, is the clearest solution to the issues raised in these petitions. We believe as a matter of fairness that individuals who have suffered serious, long-term harm as a result of NHS treatment should receive some practical assistance. We also believe that this solution is required for reasons of consistency, in recognition of the fact that HIV sufferers already receive assistance under clearly analogous circumstances, via the Macfarlane Trust."

That report resulted in an expert group on financial and other support chaired by Lord Ross.

MR WRIGHT: Yes.

MS FRASER BUTLIN: You -- am I right, you weren't a member of that group but Philip Dolan was?

MR WRIGHT: Yes.

MS FRASER BUTLIN: When the Ross Committee was established, what expectations did you and the rest of the infected and affected community have for that committee?

MR WRIGHT: Well, I think I may have fed into the thinking on the terms of reference at the time. But actually we'd taken some messages to both Government and Lord Ross about -- that this wasn't just about money. For example, one of the findings of the Ross committee is about palliative care. And that's because the experiences of people of end of life with hepatitis C had been particularly traumatic -- and continue to be so, I'm afraid, in terms of some of the experiences. And a lot of the thinking that was fed in, not just by Philip and Frank and anonymous member AA, came from us. And -- I mean, I'm reluctant to in any way pre-determine the findings of this Inquiry, but I think Lord Ross had a lot of answers that, if they'd been implemented at the time -- which is why, frankly, sir, we came up with this ten years later in terms of our analysis.

MS FRASER BUTLIN: In just one moment, Bill, we're going to get there.

MR WRIGHT: Okay.

MS FRASER BUTLIN: But in terms of expectations of you and the community, were you expecting that the recommendations would go somewhere?

MR WRIGHT: Yes.

MS FRASER BUTLIN: Would be implemented?

MR WRIGHT: Of course.

MS FRASER BUTLIN: So we then have the document that you wanted us to have up, WITN2287031.

I should say that obviously the Inquiry has already looked at the Ross Report in other hearings, so if we look at this document we can pick up some of the points you raise, Bill.

It's a document that Haemophilia Scotland produced ten years from the Ross report.

If we could go to the next page, please, Soumik.

Bill, tell us what this is and what it shows.

MR WRIGHT: Well, Dan and I, our chief executive, commissioned a -- I don't know if I can name her. We commissioned someone, we paid them, who was very well acquitted to actually look at what -- Lord Ross's recommendations and then investigate what had actually happened. That was what was behind this document. It was a bit of a lobbying document in 2013/14.

MS FRASER BUTLIN: And if we just look at the first page that the table -- Soumik, just little bit further down -- we can see that the financial help elements that Lord Ross recommended is on the left-hand side of the screen: an initial lump sum of £10,000, an additional lump sum of £40,000 for those who develop chronic hepatitis C, to cover pain and suffering, and

then "compensation to be calculated under principles of common law damages", et cetera.

Then, on the right-hand side, you've marked in red where nothing has been implemented, and in yellow, those that are in the process of being implemented.

If we -- so we can see what Lord Ross recommended in terms of financial help. As you have said already in your evidence, Bill, on 29 August 2003, it was announced that there would be the Skipton Fund as a UK-wide scheme. Were you expecting that announcement?

MR WRIGHT: No.

MS FRASER BUTLIN: What was your feeling when that announcement was made, having just had the Lord Ross Report?

MR WRIGHT: This was taking us back to London. This was taking us back to pre-devolution position.

MS FRASER BUTLIN: And I'm sure it's obvious to you, Bill, but why was that so problematic?

MR WRIGHT: Well, one of the huge benefits of Scottish Parliament is that we were able to nail them. We were able to -- I hate the expression, but hold feet to fire.

And actually, in the case of some MSPs -- and we'll see the difference there was in culture compared

to the Susan Deacon party whip period from 1999 to 2000 to those opposition MSPs during that period, who later became very senior ministers, in terms of their attitude and approach to the whole matter, that -- the contrast between that Susan Deacon-type approach and what was said on 26th March 2015 couldn't be more stark.

And, I mean, I -- the Scottish Parliament has been everything to us. And it -- there's different experiences. I know that Simon's had different experiences in Northern Ireland and Lynne's had different experiences in Wales, but any progress we've made in Scotland has been due to the existence of the Scottish Parliament.

MS FRASER BUTLIN: Have you been able to glean any insight into why the recommendations of the Ross Report weren't followed by those setting up the Skipton Fund?

MR WRIGHT: No.

MS FRASER BUTLIN: At the time that Skipton was being set up, there were suggestions that waivers would have to be signed.

MR WRIGHT: [Laughs]

MS FRASER BUTLIN: And you wrote to The Herald about this.

If we can have ILIT0000660, please.

Sorry, it's a slightly strange copy because it's

taken from the website, but we can see at the bottom -- could we take that down, please.

MR WRIGHT: I wasn't buying a pair of sandals, sir.

SIR BRIAN LANGSTAFF: No, I think it was something else that was causing it to be taken down.

MS FRASER BUTLIN: There was a difficulty. What I'll do, sir, is I'll simply read the letter that Bill wrote to the newspaper:

"The latest revelations on hepatitis C show that the Scottish Executive has sunk to a new low in how it's dealing with this vexed affair. On the one hand, it's making a derisory financial offer to haemophiliacs, which does not admit to any legal responsibility for their being contaminated through NHS blood products with this sometimes fatal virus. On the other hand, it seeks to deny haemophiliacs their future legal rights, should it be found that they collectively or individually have a case against the Executive. The only logical conclusion, therefore, is that the Executive is aware that haemophiliacs might have a legal case against it. Otherwise, if it's so certain of its innocent position why build in the clause that signs haemophiliacs' rights away? The Executive has of course also denied legal aid to those affected.

"Most living haemophiliacs could have received at least £50,000 under the recommendations of the ministerial appointed expert working group chaired by Lord Ross. They will now have to decide whether they not only settle for the Westminster controlled offer from the Health Minister, Malcolm Chisholm, which for many is less than half of what Lord Ross recommended, but also sign their life away."

That was the letter you wrote to The Herald. Were they the views of the wider infected and affected community as well?

MR WRIGHT: Yes, we were all grumpy Scotsmen at that point.

SIR BRIAN LANGSTAFF: Can you just help me: was there any official reaction, published reaction, to the Ross Report?

MR WRIGHT: [Laughs]. I think this --

SIR BRIAN LANGSTAFF: Considered reaction, I mean.

MR WRIGHT: I would need to write to you, sir, about that. Unfortunately, I'm -- the horrible words "I cannot recollect" is the situation there.

MS FRASER BUTLIN: In terms of your letter to The Herald, did you get any response from anyone within the Scottish Government, the Scottish Parliament, about that issue of waivers?

MR WRIGHT: Well, we got a reaction in their actions, in that they backed down. I've not suggested that one letter to The Scotsman from me achieved that, but yeah, they backed down.

MS FRASER BUTLIN: During this time, post the Ross Report, you were advocating in Scotland and seeking to build support across the political spectrum.

MR WRIGHT: Yes.

MS FRASER BUTLIN: You have already noted you had particular support from some MSPs, I think you were referring to Nicola Sturgeon and Shona Robison. At this point in time, when they were in opposition, can you tell us briefly what they did to support your work?

MR WRIGHT: Well, you simply need to look at the minutes of the Health Committee during those periods in that they were terrier-like in not accepting that this needed to be pushed to the courts, or in -- they effectively were in support at various different times, of both the petitions. And I think, initially, there was reference there that the Health Committee in the early -- the first Health Committee wasn't supportive of an inquiry. A subsequent Health Committee prior to 2007 when Andrew Kerr was Health Minister were in support of an inquiry, and you'll see

that Shona Robison in particular at that point was strongly in support. But also, in terms of -- in earlier times, Nicola Sturgeon asked some very searching questions of Government, via the Health Committee. I was also very fortunate in that my own MSP was John Swinney, who went on to become the Deputy First Minister and also, at the critical period in 2016, when the financial review took place, that he was Finance Minister at that point. If you look at the Parliamentary record in Scotland, he actually, in supporting the idea -- in our support, he refers to -- and I think this is characteristic of the different position that was being taken by opposition MSPs to an intransigent Government. He referred to the words that are on the mace of the Scottish Parliament -- big silver mace like the one you have in Westminster -- and those words are "Wisdom, justice" -- [laughs] -- "compassion and integrity".

Now, John Swinney used those words and that's in stark contrast and I think those words are extremely valuable in all of this. And he drew on those words at that time, and that was in very stark contrast to what we were facing. So we'd got these three people and, I hasten to add, we'd also got people like Margaret Smith and the Liberal Democrats, we were

talking to backbench Tories, we were talking to Labour Party MSPs as well. In fact, at one point the Scottish Socialists had seven MSPs in the Scottish Parliament and a woman called Carolyn Leckie, who was an MSP, was very supportive of us, so we were working very hard in the Parliament, and Bruce referred to it yesterday, to gain their support. But those three individuals were particularly critical because they'd seen the story, they had learned the story during their period of opposition and they then went on to become First Minister, Finance Minister, and Health Minister.

MS FRASER BUTLIN: I want to pick up in 2005, 2006, which was also the point in time you've said in your statement when you withdrew from active involvement in advocacy.

MR WRIGHT: Mm.

MS FRASER BUTLIN: Can we look at some documents from that period of time first and then I want to ask you some questions about them. If we could have WITN2287040, please. Second page, please.

We can see of the date, 16 June 2006 and, in the very first paragraph, this is a letter I should have said from Mr Andy Kerr. The first, at paragraph -- indicates that he is:

"... writing in response to [a] letter ... on the decision of the Health Committee to call for a full judicial inquiry into infection with Hepatitis C through NHS treatment, with a particular focus on the efficacy of the 'look-back' exercise."

He says:

"I have put on record on a number of occasions our sympathy for those who have contracted Hepatitis C through NHS treatment. This has had serious consequences for the lives of many people, and we do not underestimate or minimise these consequences."

He then speaks about the look-back exercise, communication with patients and testing for hepatitis C. Then if we pick up on internal page 5, please. Sorry, the next page, please. Under the heading "Public Inquiry":

"I cannot accept that there is any need for a full public inquiry into the infection of patients with Hepatitis C through treatment with NHS blood and blood products."

Then a few paragraphs further down:

"A full judicial inquiry would be a major and time-consuming exercise which would depend on the recollections of witnesses about events which took place twenty or more years ago. This would make it

difficult to construct a clear and detailed picture of what took place.

"An inquiry would not add significantly to our understanding of how the blood supply became infected with Hepatitis C, or the steps needed to deal with problems of this kind now or in the future."

Then the final paragraph of the letter:

"I have considered very carefully the points which were put before the Committee, and discussed by it on 18 April. I do not believe a public inquiry would either uncover any new evidence or information that is relevant to the causes of the infection of NHS patients through blood and blood products, or lead to significant lessons for the future. It would be a diversion of effort from delivering and improving health services today. I cannot see that there is any possible justification for the efforts and costs that would be involved, or that this would bring any benefit to the patients involved."

Then one more document before I ask you a question about this, Bill. You were then sent a copy of this as well, and if we can look at the letter that you received, WITN2287042. Thank you.

If we just look at his last paragraph, in which he says:

"I have had to reach a balanced view on the justification, or otherwise, for a public inquiry into these events. This has been a difficult decision for me, but I have concluded that an inquiry would be unlikely to uncover any new evidence or lead to significant lessons for the future. It would also depend on the recollections of witnesses about events which took place twenty or more years ago. An inquiry would also place major pressure on our blood transfusion service and would not add significantly to our understanding of how the blood supply became infected with Hepatitis C; rather it would be a diversion of effort from delivering and improving health services today."

Bill, when you received this letter, and the fuller letter that we've looked at, what was the impact of that on you?

MR WRIGHT: Can we just check the date on this again, please?

MS FRASER BUTLIN: It's April 2007.

MR WRIGHT: Yeah. This coincided with -- I really would wish to avoid going into -- I'd had quite a dark period in my life personally, in the lead-up to the end of 2005. I was later that year to attempt interferon treatment for the fourth time and I had

a collapse in my physical health. The culmination of -- frankly I got completely fed up with this stuff and I can't avoid saying it, sir, but I would really welcome Mr Kerr -- can we go back to the paragraph, please, I'm sorry, but I would really welcome it if Mr Kerr were asked to come and appear --

SIR BRIAN LANGSTAFF: We're going back to the paragraph. The last paragraph, do you want?

MR WRIGHT: Yeah:

"It would also depend on the recollections of witnesses about events which took place twenty or more years ago."

So hang on, if you add on 14 years to 20, that's 34. I'd really welcome it if he comes and appeared before you and established if he still was of that opinion, that he had back then. Sorry, sir.

MS FRASER BUTLIN: It's fair to say, isn't it, that at this point personally things were very difficult but it was also at a time when you with through from active advocacy?

MR WRIGHT: Yes. Yeah. It was a very difficult time. I also, after the fourth attempt at interferon treatment, there was effectively a collapse in my -- I suffered enormous fatigue and, having experienced what I'd had -- I'd experienced in the lead-up to the

end of 2005, I wanted to protect my, effectively, mental health, and I had to give up work, actually, eventually, because of the collapse in my physical health, and it took me another three or four years before I was able to get to the point where at least I could get through a day with a sleep in the afternoon and -- you know, and then I started to play golf, and so on and so forth.

So it just had become -- the Penrose Inquiry of course then came along in 2008, and I was engaged in that as a Core Participant. But I didn't -- I wasn't involved with the Scottish Haemophilia Groups Forum or people like Bruce, or Alice, or whoever, during that period. I was trying to, I guess -- and my wife was trying to protect me during that period.

MS FRASER BUTLIN: Mr Kerr, sir, has provided a response to Bill's statement and it will be published on our website in due course. He states that he's disappointed at the characterisation of his position during this period on this very sensitive matter, the whole issue has been devastating for individuals and their loved ones. He reiterates his view that, on the basis of the evidence and information before him, he didn't believe that a public inquiry in Scotland would either uncover any new evidence or information that

was relevant to the causes of the infection, or lead to significant lessons for the future.

SIR BRIAN LANGSTAFF: Does he answer the question which Mr Wright has posed, whether he is still of the same view today?

MS FRASER BUTLIN: Sir, no, he doesn't.

Sir, I am about to pause in relation to Scotland and move on to some other matters in the timeline and I wonder if now is a good time to take a break?

SIR BRIAN LANGSTAFF: Yes, certainly. Well, we will take a break until ten to 12.

(11.20 am)

(A short break)

(11.50 am)

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: I just want to make sure that we have Simon back with us as well.

SIR BRIAN LANGSTAFF: Yes, he is.

MR HAMILTON: Yes, thank you.

MS FRASER BUTLIN: There he is.

Lynne, can I turn to you, and what was happening for you in Wales. Following the Archer Inquiry, a recommendation was made that the Haemophilia Alliance would be established. And you attended -- that was in 2009. You attended for the first time on

14th November 2011 as a patient representative.

MS KELLY: Yes.

MS FRASER BUTLIN: Knowing about the Haemophilia Alliance, what were your expectations of those meetings?

MS KELLY: Well, I thought that when the Archer recommendations were made, that the Alliance was meant to be a group comprising of patients, clinicians, Department of Health; and that group, as per Archer was meant to include issues about care and support. But when I went to those meetings, they'd already been going on for two years -- you know, I didn't start going until 2011 -- and support had been omitted from the terms of reference.

So that was a concern to me. My cousin had just died so obviously we'd lived through the experience of a family member dying. And I felt that all the issues that I'd gathered from the patients in Wales regarding, obviously, lack of financial support, lack of provision for hepatology, monitoring of hepatology, there just wasn't an appetite at those meetings for those issues to be covered.

I went obviously as a Welsh representative, and my feeling was that they saw Wales as very much a side issue, and that was something that needed to be sorted out in Wales, whereas I felt if the cohort were

infected, you know, UK-wide, I knew there would be other people who were in the same position as my own family had been in, and many other people that I'd spoken to and gathered experience from in Wales. But I found that the Department of Health meetings -- you know, the chair was -- the Department of Health -- can I say the names?

MS FRASER BUTLIN: I don't believe it's been redacted so yes.

MS KELLY: Right. So the chair of the meeting was Rowena Jecock, who was head of Blood Policy, and in her absence Ben Cole would take over. They were jointly chaired by The Haemophilia Society. But basically the whole day would be taken up by some sort of Department of Health, it would be -- there would always be presentations by the Department of Health, and you wouldn't really know you were in a meeting to do with haemophilia or infected blood or any of those issues. And then I just felt that there were no real focus on the issues that I knew were affecting the community in the Wales, and as I say, I thought the same would be happening in the UK.

And at those meetings I met many people from England -- I actually met somebody from Scotland as well, but not Bill, and basically they were all saying

the same things, that they were coming to those meetings, they were desperate. There were people dying and they were trying to get to the meetings. They'd travel for miles and miles to get there, expecting that there would be some -- something done. They'd think that if they told the Department of Health what was going on, they really felt that something would be done. But it all fell on deaf ears. We'd find that, during the course of the time I was attending, the minutes would never be circulated. We wouldn't get an agenda. You'd be missed off the circulation list.

I just felt that I was perceived as a bit of a troublemaker, really, because I'd go with my list of issues. I'd present on the issues that were affecting people in Wales. So basically they'd just move it on to the next item and say, "Oh, well, that's a Welsh problem."

Do you want me to go on?

MS FRASER BUTLIN: We're going to come to the specific issues, the clinical issues that you campaigned on in Wales towards the end of the evidence today, because it's a very important part of your evidence. But just staying with the Haemophilia Alliance and how that was functioning, you've said you were perceived as

a troublemaker. How did you get that perception?

MS KELLY: Well, basically because there would be the Department of Health officials, the haemophilia doctors. There weren't any Welsh haemophilia doctors there so, you know, I didn't personally know them. But it was very much -- they'd look at each other and think: oh, well, that's your problem, you know, that isn't really our problem.

And I was arguing for a national policy. If they had put this into the national service specification on haemophilia, where people with contaminated blood had access, not just to hepatology services. We were asking for access to consultant hepatology opinion, because we knew so many were dying and they weren't being monitored, they weren't being diagnosed with advanced liver disease, and basically, by the time it was picked up, they were presenting at A&E, you know, swollen, with ascites, on trolleys, without beds. And all the people were saying the same thing. But the haemophilia doctors, it was as if it was a separate issue. It was a side issue to them.

And that wasn't the position of our clinicians in Wales. We had good support from them, because obviously they knew their patients very well. Our centres are, you know, relatively small to compared to

England. And I just couldn't believe that -- you know, as well as the Department of Health, there was the UKHCDO. They didn't seem to want to address any of the problems. The Haemophilia Society would come to the meetings and they'd present on some other initiative -- some or other initiative they were trying to, you know, get funding for at the time.

I just felt it was sickening, really, that people were coming, and they were desperate, and I actually met -- it's one of the campaigners, and I didn't know they were related at the time, but his uncle, and he'd come to the meeting and, you know, he was waiting on a liver transplant and he wanted some answers from these people, and they'd just keep saying: "Well, we can't distinguish between route of infection, you know. You shouldn't be having priority over other people."

And we would say: "Well, yes, we should, because, you know, we were infected, infected by the State, infected by the NHS. It's not covered in the haemophilia care, it's not in the national service specification."

And that would have been a way that they could have come together and had a national policy on how to deal with this cohort of people. And from what we'd

seen in Wales there were massive gaps in care. And basically people were just dying. They'd been admitted through A&E. Their deaths weren't being recorded as attributable to liver disease or liver failure. The Department of Health -- that was another issue, I always brought it up with them: why don't you record the cause of death? They would just record the fact of death, and they'd put the onus back onto the doctor who was there at the death.

MS FRASER BUTLIN: Why was that so important to you, Lynne?

MS KELLY: Well, because it had to be documented that they were dying as a result of infected blood, and that wasn't happening. So unless the family specifically asked for "Can you put HIV" or "Can you put hepatitis C on the death certificate", that wasn't happening. Obviously I do know about -- you know, there are families who didn't want HIV -- you know, obviously I know the group very well -- but the hepatitis C was a real issue.

I just felt that those deaths, and -- you know, from liver disease, it was just swept under the carpet. They just grouped them all with the same cohort of people who were, you know, alcohol, drugs, whatever. There was no priority given. And, you

know, knowing the people, knowing the people who died, the stigma was terrible, because that left such a lasting effect on the family, the fact that their loved one had died, and the nurse who was looking after them on a general ward didn't even know how they became infected.

You know, it happened with my own cousin as well. There was -- you know, the nurse is, "Oh, you know, you can't touch him, he's got hep C, wear gloves", and that was said, you know, in the open.

MS FRASER BUTLIN: In the Haemophilia Alliance meetings, you've said that a lot of things were seen as a Welsh issue?

MS KELLY: Yes.

MS FRASER BUTLIN: How involved were the Welsh Government or officials in those meetings?

MS KELLY: Well, at that point, at the very beginning, before we, you know, before we sort of told them -- we weren't happy about it then, Welsh Government were really disinterested in it. They were invited to the meetings, but they would come to meetings -- I remember one particular meeting where there was some patients who were quite ill; Welsh Government reported back to the meeting that there was no progress, but we'd actually had a major breakthrough and we'd had

a hepatology appointment made in Wales.

So they didn't really know what was going on, basically. And I felt that they weren't really interested at the time.

MS FRASER BUTLIN: And just a moment ago you said that financial support was included from the remit of the Haemophilia Alliance.

MS KELLY: Yes.

MS FRASER BUTLIN: Was that ever raised at any of the meetings you --

MS KELLY: Yeah, I raised it a lot. But it was never minuted, like lots of things weren't minuted, and they would just say, "It's not within our remit". So any discussion about money or finance was just excluded.

MS FRASER BUTLIN: It was later decided that the Haemophilia Alliance would be replaced by clinical reference groups. What was the effect of that on Welsh patients?

MS KELLY: Well, I strongly objected to that. And the last meeting I attended, I made -- you know, I did make a big fuss about that, because I said we have no -- we don't have a UK-wide group now, as Archer intended. This was meant to be a group that came together with patients, you know, who were experts in their condition. Haemophilia clinicians, should have

been -- hepatologists should have been on that group, HIV specialists, dentists should have been there. All those gaps in care with haemophilia that everybody was experiencing, that was the forum for it. And it was meant to be -- you know, you're meant to -- an exchange of good practice around the UK.

In the last meeting I attended, I really, you know, stood up and said, "Look, this is just -- shouldn't happen", and nobody supported me. I just was the only one in the meeting who wanted the Haemophilia Alliance to go on, because I felt, well, for Wales, we'd lost that contact. Scotland, the same. Obviously Northern Ireland. All the devolved powers. Because our care in Wales is managed differently. We don't have CRGs; we have WHSCC, who are the Welsh Health Specialist Services Commission, so they're in charge of haemophilia care in Wales, so we had no forum to take any of our issues to.

MS FRASER BUTLIN: And so, I think in your statement the sense is that there was the Archer recommendation, and the Haemophilia Alliance in that petered out?

MS KELLY: That petered out. And, you know, that was done for a reason, because basically, my opinion is that they didn't want to resolve the issues. They wanted to sweep the whole infected blood cohort under the

carpet.

And as each family -- as a family member dies, lots of people drop away, and I think bit by bit they thought they'd all be dead and there would be nothing to do. And, you know, the haemophilia doctors that I saw at the Haemophilia Alliance, they obviously -- you know, they had patients with infected blood, but I felt the fact that they couldn't relate to that with the stories that we had from Wales, and there was nobody representing us from Wales except me, I just felt that they -- you know, they didn't really show any concern about that.

We had issues regarding endoscopies, where people couldn't get access to endoscopies when they were in -- you know, when they had cirrhosis. They were denied access to that because of the variant CJD. I took a letter to the -- one of the Haemophilia Alliance meetings about that and, again, they said it's a Welsh problem. But this had actually happened in Birmingham. Because that was the liver specialist centre that our patients would go to from Wales.

And it would have been so easy to resolve, to have a strategy in place where all this group of patients -- there are not that many of them -- were looked after, you know, and they had the care that

they were entitled to.

MS FRASER BUTLIN: In terms of the chronology, we've talked a little bit about the Archer and the outcomes, the recommendation from that.

That takes us back, Bill, to you, in terms of the Penrose Inquiry.

If we pick up in about 2011, when you really returned, it seems, to the fray of advocacy and campaigning, prior to that you'd been writing letters to MSPs to press for the Inquiry and press for progress with the Inquiry, but if I can pick up your position as chair of the Scottish Management Committee in 2011. We'll pick up there.

Part of your work at that point was to rebuild the political connections that had previously existed; is that right?

MR WRIGHT: That's correct.

MS FRASER BUTLIN: So you've said in your statement that in 2012 and 2013, you held some Parliamentary briefings, including one in April 2013, where Alex Neil spoke about what the Government intended to do after Penrose was published.

MR WRIGHT: Yeah, the way things work in Scottish Parliament is that it was trying to -- the new Parliament had tried to make itself open and

accessible. So if an MSP -- and I have to pay tribute to Richard, the former MSP Richard Lyle, here, he organised for us to have several presentations to MSPs actually, one of them was memorable. It was actually in the garden lobby of the Scottish Parliament. I happen to think it's a magnificent building and that's where everybody gets together. It would be a bit like -- well, I'm not that familiar with the Houses of Parliament but the great hall, or whatever, the place where people go. And it was extraordinary because we actually got 20 MSPs along, I think, to the first one, and Alex Neil came and spoke and he spoke at a subsequent one in one of the committee rooms.

So we'd got not only MSPs hooked in but we'd got ministers hooked in by this point.

MS FRASER BUTLIN: As an organisation, Haemophilia Scotland were gradually drawn into the Inquiry as well --

MR WRIGHT: Yes.

MS FRASER BUTLIN: -- and became a Core Participant in February 2014.

MR WRIGHT: Yes.

MS FRASER BUTLIN: We'll come to the interactions with the MSPs after the Penrose Report in a moment and you'll be aware that this Inquiry is not an inquiry into

an inquiry. But thinking about the process of the Inquiry and the report itself, I want to ask you what the impact of the Penrose Inquiry was on you.

MR WRIGHT: Exhausting. Utterly exhausting. And that very much coloured our judgment when this -- there were proposals coming about for this particular Inquiry, and we learned so much from the Penrose Inquiry, not necessarily from its report, albeit there was a substantial body of evidence that came forward that clearly this Inquiry, in its PRAC documents is drawing upon, but we learned about -- I'd written a letter to the then Health Minister, Nicola Sturgeon, which is one of my submissions, where I made various suggestions about what should happen in terms of the conduct of the Penrose Inquiry.

I suggested, for example, that we use the Web. Most people that our watching today are not in this room, they're on the Web. Now, Scotland is still a pretty big country stretching from Shetland down to the Borders, and Lord Penrose didn't accede to that. He wasn't that keen on the press attending. You know, I was very keen that this was a public Inquiry, and remarks were made by the chair of that Inquiry at times about the presence of the press and media.

We weren't actually funded to go and watch, so

we weren't getting -- seeing the Inquiry on the Web, we weren't being funded to actually attend it as people are here today and, in terms of the evidence, Lord Penrose was very much leaning toward anonymity on the part of us who'd been infected or affected. We didn't have the choice. I would have been perfectly happy to be Bill Wright in my statements but everything was redacted.

The witnesses who appeared in total, unlike -- there's been a huge number of witnesses appeared here, of people who have been affected and infected. I'm looking at some, and there were only, I think -- Philip, the dear departed Philip said about six, it was actually a bit more than that, I think it was about 12 or 14, so you didn't get the impact of the personal stories in the way that there has been in this Inquiry, and that was really hard because we didn't feel we were being listened to.

So we didn't get that personal input. The terms of reference I'd made various suggestions about. One of the -- we'd expected, when the -- there was a terms of reference about examining matters generally and we felt that that was an enabling term, in order to -- for Lord Penrose to look quite widely at the various issues that arose around it. He narrowed that right

down, and I had personal experience of that in relation to my own story, that the word "generally" -- he always wanted to keep things general, rather than look at individual stories and put the pieces of the jigsaw together in that respect, in terms of people's different experiences.

So I also -- I have to confess, I'm experiencing from time to time similar experience with this Inquiry, the issue of pace, it felt like our counsel was asked to respond to huge long documents within a few days. They came to us for instructions, and we tried to respond. I was in the Island of Colonsay at one point, and you can imagine, you know, what the broadband connections are in the Isle of Colonsay, and it was a matter that I knew particularly about.

So my wife and I were staying in a self-catering accommodation, we were dashing backwards and forwards to the local hotel trying to sort of, you know, talk to Thompsons Solicitors, and to email them, and it was a nightmare, whereas it felt like Lord Penrose gave himself quite a number of months at times, to deal with various issues.

MS FRASER BUTLIN: You've said the impact on you was exhaustion.

MR WRIGHT: Yeah.

MS FRASER BUTLIN: Is there anything else you want to say about the impact on you personally, how it felt?

MR WRIGHT: It did colour my judgment towards inquiries. And we'll come on to the dramatic week that the report came out, which I will never forget -- boy. But I think the period of Maxwellisation, the two-and-a-half years between the final sitting and the day the Report came out, was a weird, weird, weird time, because it came out March 2015 and the final hearing, which was an additional hearing that frankly would force Lord Penrose back to the -- back to a public hearing about statistics, and that was a really grim day, because unfortunately, sadly lord Penrose had just had some very bad news about the health of his wife, he wasn't in the best of moods that day.

But that period between October, when we were developing as a charity, and March 2015 was a very strange time because we'd had this frustrated period where -- I haven't necessarily got the correct terms of reference, they weren't looking at, for example, financial support, they were never within the terms of reference of Penrose, rightly or wrongly.

I think, at the time, we kind of felt that we'd had these undertakings from Alex Neil and his

successor that they would look at it at the end of the Inquiry. We didn't think we were going to have to wait two-and-a-half years for that report to come through, and that was problematic for us, because people were still dying during that period. And there is a particular instance of someone who died.

There was another really weird situation in that there was a sort of Core Participants group that Thompsons drew together in order to take soundings from us. It was about something like a dozen, 14 people. So we meet in this room in Thompsons, and counsel was there. Counsel would instruct us "You're not allowed to tell each other what your names are". That was the degree of anonymity that was forced upon us by the chair. In other words, he said, "You cannot identify each other".

So we had this weird thing that more than half of us knew each other and we were sort of saying, "Well, I'm going to tell" -- you know, it was really weird. I mean, these were people we knew really well, and so we had this weird sort of situation that we were sort of giving our views on. It was a weird and difficult, difficult time.

MS FRASER BUTLIN: That evidence, Bill, is that a reflection of your own experience of the impact

of it or do you draw on the broader impact on the infected and affected community in Scotland? Was that the similar experience of the rest of the Scottish community?

MR WRIGHT: I would say there was a lot of frustration. And I pay tribute to -- there's an individual here today who was involved in the briefing group that instructed -- the sort of working group that I wasn't initially involved in, and people like Bruce and Alice and Philip, who gave some really good input into the Inquiry. But whether it was listened to, I'm not sure.

MS FRASER BUTLIN: The report, as you say, came out on 25 March 2015. That afternoon there was a private gathering of Haemophilia Scotland --

MR WRIGHT: Yes.

MS FRASER BUTLIN: -- together with Nicola Sturgeon and Shona Robison.

MR WRIGHT: Yes.

MS FRASER BUTLIN: Can you tell us what happened at that gathering?

MR WRIGHT: Well, I'll never ever forget that day and the following day, and the week running up to it.

Might I set the context here, in terms of what had happened in the morning?

We'd, as Core Participants, been given advanced sight of the report and we knew in Scotland that this was going to be really, really bad news. One single recommendation from a £12 million inquiry. And we were looking at this, and we're thinking: wow, what do we do here?

However, what we also knew was that we had supportive ministers, and -- so we got to that morning -- we'd already been working very hard that week to read the report, talk to solicitors, prepare the press and media, because we'd organised a press conference that morning.

And I think you were there, Lynne, that morning --

MS KELLY: Yes, I was there --

MR WRIGHT: -- at the press conference when the report was presented. And the report was presented by the Secretary to the Inquiry, and -- there were sort of two tiers. There were people who had come from Wales and England, who hadn't been Core Participants, who were shouting "Whitewash!" And this poor relatively junior member of staff had had to present this. And I'm a guy in a suit and I -- what we'd decided to do, we'd been advised, is don't have a press conference in another place. Do it in the same place. And we'd

actually spoken -- we'd made contact. So we decided to make it in the same place.

So we got a whole bunch of people really angry at the back shouting "Whitewash!", we'd got the nascent press at the front, and we -- because we had to react to this publicly, so I've got the combination of people sort of wanting a bit of drama and awkward questions, press people and people just filling at the back. However, we knew, because we'd been in touch with Scottish Government, that we could move forward, because -- and I made a speech to that press conference.

And I'd gone up to this secretary and said, "That must have been dreadful for you", the poor woman. And I think some of the people at the back didn't necessarily recognise me. "Who's he?" So here's a guy in a suit, we'll just shout at him as well.

So I thought: how the hell do I rescue this? So what I did was I grabbed the Penrose -- one of these sticky things in front of the table, grabbed it, and threw it away. And I think that actually -- that did get to the television that night, in ITV and BBC. And then I started to make my presentation, so -- however -- we'd decided that we had to deal with the

press and media. However, we knew that people were going to be very, very upset, and Dan and I and others had talked around this and we thought -- people need to go to a quiet place in such circumstances.

So what we did was we organised a get-together along the road -- and I think you maybe came to that as well, Lynne?

MS KELLY: I came, yeah.

MR WRIGHT: In fact you that the opportunity to speak to a minister.

MS KELLY: I did, yes.

MR WRIGHT: And what we'd organised was for the First Minister and the Health Minister to come and meet people without the press there. And that was so important to do that, because that way you get in your face the real stories, when people have settled down, and they start to tell the stories.

And I remember Shona Robison, the Health Minister, saying afterwards, "It was those women that made me want to act". She sat at a table, I remember -- actually, my wife was sitting at another table and she said to me, "Who is that woman who was sitting at the table with us?" And I said, "That was Maureen Watt", the Public Health Minister, junior minister to Shona Robison. I think John Swinney might

have been there as well.

So we were working away to get these messages over. And the good thing is that the likes of Lynne was able to bring Welsh experience as well. So that was the start of a whole new chapter, and a very important chapter for us.

MS FRASER BUTLIN: And the next day a question was asked in the Scottish Parliament.

If we can go to that WITN2287078, please. Page 2, please.

We can see on the right-hand column, the heading "Penrose Inquiry", and Nicola Sturgeon was asked what the Government's position was on the Penrose Inquiry, and she was challenged that it was a whitewash.

If we go to the bottom of the second column, we can see her response about the question of it being a whitewash.

"I can obviously understand the feelings, frustration and, even, disappointment of all those who are affected by the dreadful events. However, I was struck particularly by comments that Bill Wright of Haemophilia Scotland made yesterday. I thought that he was correct in his assessment that, despite his disappointment,

"'there is a narrative setting out the case that

cannot be avoided by the government and its moral responsibility.'

"On behalf of the Scottish Government, I certainly accept that responsibility."

And it carries on:

"Taking account of the wider findings of the report, and in consultation with patients and families, we will act to implement the report's recommendation and take forward the review of financial support as a matter of urgency."

And that afternoon Shona Robison made an announcement in the Scottish Parliament, didn't she, that further work would be done on financial support and in relation to additional psychological support.

That, as you say, was the start of a different phase in Scotland; is that fair?

MR WRIGHT: Can I just say two things about this? First of all, until this point, until the Scottish Government felt able to move following the report from the Penrose Inquiry, we'd been facing a sort of approach that had been taken that's represented in the submission I made about Susan Deacon's comments: force them to the courts. Let's force them to the courts; we're not interested in morals, let's go to the courts.

That day, when I heard that -- and it's really funny, I was speaking to Bruce about this yesterday, I think he mentioned it in his evidence -- it's not because I was name checked but it was because there'd been -- the press conference that I'm talking about, there'd been -- we gave them a copy of what my words -- my speech. That ended up in a briefing from a senior civil servant to the First Minister, and -- about how Government was going to respond. So it wasn't the fact that I was name checked; it was these words:

"There is a narrative setting out the case that cannot be avoided by Government and its moral responsibility on behalf of the Scottish Government. I certainly accept that responsibility."

That is one hell of a thing for any politician to hang themselves with. And I remember at that point, I had to leave the chamber. Here I was, a middle-aged grumpy Scotsman, I was exhausted and I ended up howling like a baby because, like Bruce -- what I didn't realise was that he was howling as well. And Susan grabbed me and hugged me, and I -- all the way down in that lift, I wept my eyes out because I knew that that was the big breakthrough for us in Scotland. Because of those words.

And, of course, we then went on to have a dialogue, a proper constructive dialogue with Government that I hope to hell Sir Robert Francis has with people here, when it comes about the announcements in -- we follow up in the announcements in March.

So Bruce was -- what I didn't realise, Bruce was howling, I was exhausted, and then we had to go and meet the Minister in the afternoon, a group of us, and talk about what happened next.

We had already made proposals to the Minister about what happened next, and it had to be an inclusive process, unlike the bit that I've missed here, was the David Cameron response. At the very same time as I was on my hind legs in Edinburgh, the Prime Minister was in London saying, "I apologise". He didn't actually explain what he was apologising for. My bet is that the First Minister in Scotland would have a better idea about what she was apologising for and the Scottish National Blood Transfusion Service would have a better idea about what they were apologising for than Mr Cameron in London, because he also said, "Well, here's an extra 25 million".

This is the wrong -- I'm sorry, sir, but this is

the wrong way to do Government! You have to engage with people. You don't just throw money at people.

I wrote a letter that night, I was up all the night, all night, between the 25th and 26th, writing this letter to David Cameron. The Haemophilia Society were a bit annoyed because I'd got in before them, but that's old history. And I asked him questions "Where does this figure of 25 million come from? What's it for? How's it arrived at?" I never got an answer.

No answer from the Prime Minister. I learned from a journalist that was at the press conference that day about that announcement that was taking place hundreds of miles away. Where's the decency in all of this?

I'm sorry, sir.

SIR BRIAN LANGSTAFF: What are you sorry for?

MR WRIGHT: I can become very passionate about that particular episode.

SIR BRIAN LANGSTAFF: That's part of giving evidence, I think.

MR WRIGHT: I mean, what the hell was going through Cameron's mind, for Christ sake? What was his briefing? Where were these people? Were they talking to us? 25 -- oh yeah, just -- let's give them £25 million.

The journalist says to me, "David Cameron has just announced an extra £25 million, how do you react to that?" I'm sitting there with all these people there. And I said, "That's a damned insult", I had to think on my feet. There are some people here that were there at that moment and The Times journalist came back to me and said, "Well, what do you think is a fair amount?" and I said, "That's something that we will discuss, with due respect to you, directly with Government, not via the press and we will try and engage people in that process, the people who have been infected".

And that's why I feel very strongly that in the exercise that's about to come about here, announced in March, that everyone in this room, and everyone out there watching this, feels they have some ownership in. That is good government. Taking views, taking ideas, not just chucking money. I mean, 25 million? It was a damned insult. I stand by that. Sorry.

MS FRASER BUTLIN: You don't need to apologise, Bill. I'm going to pick up financial recompense in a moment. I want to turn to Lynne and Simon in relation to a couple of matters in relation to the Public Inquiry.

Lynne, if I can pick up with you, just before the Penrose Report at an APPG meeting on 17

April 2013, could we have WITN3988072, it's page 5. Sorry, if we start at page 2, we can see what it is.

We can see the heading at the top, that it's the APPG on haemophilia and contaminated blood at the House of Commons, and various MPs were there. Was this a regular meeting that you attended, Lynne?

MS KELLY: Yes, yeah. I always attended. We had a lot of support from the Welsh MPs, so when it was obvious that the Archer recommendations weren't going to be implemented, we started gathering our forces, really, together, and encouraging people to write to their MPs, as well as their Assembly members, to try to address some of the issues. We were doing the same thing down in Wales as well and, at that point, we had had -- a Task and Finish Group had been recommended to address the gaps in care in Wales and I was part of that group.

And I gathered patient experiences, and they were all the things we already knew, but we had to get them documented. And then, as well as that, I obviously used to go to the all-party group because we had supportive MPs, people like Owen Smith, you know, he'd instigated the Backbench Business Debate in 2010 or 2011, but then he was promoted to become a minister, so it was Geoffrey Robinson who took over

the debate.

But we heard from all the MPs in Parliament about the real issues that were affecting their constituents, and then that led to another weak review, shall I say, by the Government, and an announcement in 2011, which meant that people weren't really any better off.

MS FRASER BUTLIN: Just pausing there, the point I want to pick up with you from this document, it's slightly different. Could we turn to page 5 of the document. At the bottom of the document, we can see your -- one of your contributions. There are many in this document but one of the contributions is you explain that an acknowledgement of what happened is what everyone wants. I think it's Jason McCartney from Colne Valley then confirmed MPs made that point in the 2010 HOC debate --

MS KELLY: Right.

MS FRASER BUTLIN: -- and there was a suggestion on the next page of another backbench business committee debate.

MS KELLY: Yes, so --

MS FRASER BUTLIN: Just in terms of that work you were doing, seeking a public inquiry and, as you say, seeking acknowledgement of what had happen, what was

happening at this time?
MS KELLY: Nothing. Nothing, really. It was the same old thing, you know. Government -- they'd have a consultation, they'd make the questions so narrow that people couldn't answer the questions or they couldn't highlight the issues they were having. We had real issues with people regarding financial support. The Government would then -- they'd just do as little as they possibly could. It would be, as Bill said, an insult. People were relying on something being done, because they -- you know, morally, as we've just heard, morally, Government had a responsibility to do that. And every time there was an announcement at Westminster, there wouldn't really be very much in the announcement but it would be, you know, a big PR exercise for the Government where they'd announce how much money they'd already given the scheme since they were set up.

Then in the devolved nations, we'd always have the same thing. Same pattern. The Minister wouldn't know that Westminster was going to make an announcement, there'd always be a delay. Because we had better communication with Welsh Government, we'd always have an opportunity to going and speak to the Welsh Government, I think it was Edwina Hart at

Julie Morgan one of them, but, you know, Mick Antoniw and Dr Dai Lloyd, they had all been involved since the beginning of the assembly, Dai Lloyd, they knew how strong the feeling was in Wales, so they started to veer away from Westminster in that regard because they heard the personal stories. And basically many people at the meetings, they were never going to benefit from financial support because they weren't included in any schemes anyway.

And the fact that we were still asking for, you know, partners to be included in the scheme after 30 years, it was just a joke, really. So Welsh Government, then, they started to support the calls for the public Inquiry. That was a big turning point. You know, obviously Julie Morgan, she led that, but it wasn't like that in Westminster. It was a battle all the way. And then, eventually, in 2017, Welsh Government voted in favour of a public inquiry, and that was a real breakthrough.
MS FRASER BUTLIN: And that was a unanimous vote by -- (overspeaking) --
MS KELLY: Yeah, a unanimous vote.
MS FRASER BUTLIN: -- on 25 January 2017.
MS KELLY: Yeah, and we had a big debate in the Assembly and we had the names of all the people who had died,

the time, and the Welsh Government would make any tweaks to whatever the announcement had been, so we would relay issues about again, monitoring, so they'd agree they'd have FibroScans to monitor --
MS FRASER BUTLIN: Just staying on the much more narrow point for now, Lynne, about the Public Inquiry and the campaign for a Public Inquiry --
MS KELLY: Yes, so there was --
MS FRASER BUTLIN: We've got this in 2013.
MS KELLY: Yes.
MS FRASER BUTLIN: I think at the time you were also having meetings and writing letters to Alun Cairns, Carwyn Jones and Vaughan Gething.
MS KELLY: Yes.
MS FRASER BUTLIN: What response did you get in relation to the seeking of a public inquiry?
MS KELLY: The Public Inquiry. Initially I would say that obviously the Welsh Government had been briefed by Westminster so they didn't feel there was any need for a public inquiry. You know, the usual thing, Archer Inquiry had said there was no fault, there would be no benefit in having another inquiry.

As a cross party group, as we gathered more and more strength with that and we had more and more meetings, obviously the key politicians in Wales,

and they ran around the Senedd as all our Assembly members spoke. The Assembly members knew all their constituents and obviously they were able to relay the stories. And we had, you know, a vote. It was a voteable motion and there was a unanimous vote for a public inquiry.

We'd had similar debates in Westminster, the Backbench Business debate we'd had, same stories about the hardship, the suffering. The MPs themselves, Welsh MPs, they -- you know, they -- obviously the same, they knew their constituents. They all supported it. But then Government would bring in a three-line whip and that would just all be decimated or they'd try and bring in a wrecking motion. They'd change the -- they'd change the -- you know, the Bill. And then we'd share in the House of Lords, then, from -- can I say Bill Howe?
MS FRASER BUTLIN: I'm not aware of the name being redacted.
MS KELLY: So the Government would introduce a wrecking motion, and you'd have the likes of Earl Howe in the House of Lords, because we were obviously lobbying at that time that it was something along the Irish settlement we were looking for, because it was a much broader scheme that included more of the affected

people. It had life assurance, mortgage protection, priority access to healthcare. And members of the House of Lords such as Lord Howe would say that -- why should they introduce that? They couldn't discriminate between the route of infection, all it would lead to would be people jumping the organ donation queue.

MS FRASER BUTLIN: Again, just returning to the question of the public Inquiry, there was the unanimous vote in the Welsh Assembly.

MS KELLY: Yes.

MS FRASER BUTLIN: Then I understand you met with Vaughan Gething on 23 November 2017 about the public Inquiry.

MS KELLY: Yes.

MS FRASER BUTLIN: Can you tell us about that.

MS KELLY: He agreed when that he would write to Jeremy Hunt, in support of a public inquiry. At that time we'd had consultations in Wales. This was after the Task and Finish Group, we had workshops around Wales, where Welsh Government met then, again, with all the families, and the stories were told again. And basically the strength of feeling was so strong that Vaughan Gething, the Health Minister, said, well, he had to write, and obviously we were delighted,

because it was a massive breakthrough. You know, there'd never been a Government that would support it. But the Welsh Government said, well, they had nowhere -- you know, that's what they had to do. They knew it wasn't going to work any other way. So that was a huge breakthrough for us.

MS FRASER BUTLIN: Just pausing there in terms of the campaign work you did for the public Inquiry. What was the impact of devolution on your campaigning?

MS KELLY: So, as far as devolution was concerned, I think it was good insofar as we had good access to Welsh Parliament. It caused confusion when an announcement was made, but it gave us the strength to lobby our Welsh Government, and obviously they supported us then in our calls for the public inquiry. So I suppose it was twofold, really.

MS FRASER BUTLIN: We're going to come back to the financial recompense in all three nations in a moment.

Simon, you've described in your statement -- thank you for your patience -- you've described in your statement --

MR HAMILTON: Not at all.

MS FRASER BUTLIN: You've described Penrose as a whitewash. To what extent did the infected and affected community in Northern Ireland hold out hope

that certain issues would also be resolved by the Penrose Inquiry?

MR HAMILTON: That's a very good question and I'll answer that in one second. If I could first of all say, having listened to Bill and Lynne, I'm in some ways a Johnny Come Lately to this process. I've been canvassing or campaigning or advocating for about six years. But to listen to their stories, they have been pioneering in setting up, with others, the context for where we are now. In terms of the situation across the devolved assemblies and in terms of the constituency of Northern Ireland, I would say haemophiliacs here have had less access to the political awareness and the political interaction that has taken place in England -- in Wales and Scotland, rather, with England. We in Northern Ireland, as a cohort of victims, as a cohort of people who have been enduring the process, have been enduring the process.

I think, to answer you very briefly, people didn't have a lot of hope. There's a difference between hope and expectation, and hope and reality. And I think most people felt this is just another go. If there is anything, if there is further consideration, we might get something, we might get

some benefit from it. But there wasn't any strong belief that we would -- we would have any issues addressed. And bear in mind the history of Northern Ireland being under direct rule.

Our Department of Health would have responded to the guide and direction from central Government, from the Department of Health in England. So that was the process, by and large. And people had come to accept their lot, reluctantly, but in reality, that appeared to be it. So we wouldn't have had a great expectation. It didn't give up hope but we wouldn't have had a great expectation.

MS FRASER BUTLIN: And after the Penrose Inquiry Report, you wrote to all Northern Irish MPs in relation to --

MR HAMILTON: Yes.

MS FRASER BUTLIN: -- a public inquiry. Can you tell us what you were seeking in those letters.

MR HAMILTON: Yeah, I did indeed. Actually, first of all, when I saw -- and I listened to what Bill was saying. I felt anger. I felt anger at what had come out of that. I felt that it had been -- underwhelming would be a very generous way of putting it. It had not achieved its aim. It had not served the people. It had not -- perhaps it served Government but it didn't serve anybody else. And I felt that there was a moral

issue at stake and the moral issue was that the Government would do what was right, and I felt personally that I should write to all the Westminster MPs in Northern Ireland to make contact with them, raise the awareness of the issues, encourage or challenge them to be more aware of the needs coming out of these failed inquiries and that haemophiliacs and people infected across the realm with the blood -- contaminated blood issues should be better served and be given a voice and their voice be recognised.

After Penrose, there was a great feeling that we'd just been beaten down.

MS FRASER BUTLIN: I want to move on to the question of financial recompense with each of you.

MS KELLY: Could I just add something, because obviously you put the APPG in front of me? What I would say is that at that meeting, I think I am right in saying it was Anna Soubry who attended that meeting. Is that the right one?

MS FRASER BUTLIN: Yes.

MS KELLY: And I would say that one of the Welsh MPs remarked that she was the worst briefed minister that he'd ever met. So she came to the meeting just completely just not briefed at all. She'd been sent the questions ahead beforehand, I think, by Diana

Johnson, she couldn't answer any of the questions, and she obviously had no understanding of what people were looking for.

So, again, it was just that lack of interest in Government, just deny it and push it away and they'll stop coming, you know. That was what I wanted to --

MS FRASER BUTLIN: Thank you. I want to move on to financial recompense and, I'm afraid, Bill, it comes back to you to start with.

MR WRIGHT: Can I stop you there? I'm not sure how long we've got to go before lunch but, this is all rather embarrassing, I might have a very quick comfort break, sir?

SIR BRIAN LANGSTAFF: Well, let's take a lunch break now, since we are going on to something else.

MR WRIGHT: Sorry, sir.

SIR BRIAN LANGSTAFF: No, don't apologise, for goodness sake. So let's come back, shall we, at ten to two?

MS FRASER BUTLIN: Thank you, sir.

SIR BRIAN LANGSTAFF: So ten to two.

MR WRIGHT: Thank you.

(12.47 pm)

(The luncheon adjournment)

(1.50 pm)

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: Thank you.

Before we look at financial recompense, Lynne, I've been asked to invite you to explore one issue we talked about this morning a little bit more.

Your experience of seeking a public inquiry. Can you tell us what -- any -- whether there were any particular obstacles you faced when you were campaigning for a public inquiry?

MS KELLY: From the very beginning. Well, I think it was the fact that the Government kept saying that there was no fault, and then, when we had the Lindsay Tribunal, obviously in Ireland they compensated on moral grounds, and they took responsibility but the Government changed that line and the Government kept saying that the situation in Ireland was different. Therefore that was repeated and repeated and repeated, so obviously all the civil servants over the years were briefed and everybody kept saying the same thing, and then that went -- the same was said in Welsh Government. They just repeated the mantra, really, that it was different and there would be no -- there was no fault, the circumstances were different.

Therefore, they'd come back and say: well, you know, there will be no public inquiry but we'll offer

a bit more assistance, really. So it was only really when it was 2015, 2016, when the Department of Health issued the proposals for financial support and they were only including widows at £10,000 each, we then thought as a charity that we had to seek legal advice on it. We tried some solicitors and we didn't find anybody, and then I wrote to barristers in Cardiff asking did they know of a barrister who could advise us legally, because we knew it was the only answer -- it was the only way of getting to the truth.

Obviously as a group of trustees we're all affected or infected volunteers and there were people there that just didn't have time to wait. So we thought, well, we'd try and get some legal advice. And the lawyers in -- the barristers in Cardiff, they said, well, you know, it was going to be expensive, obviously, to get legal advice in the first instance. And I said: well, could you -- I didn't know any barristers at the time, I just sent a general enquiry with, like, a paragraph about what we were looking for. And I said, well, could they recommend any kind solicitors who would see us free of charge?

And that's when we came into contact with Watkins & Gunn -- I can say? Yeah, so Michael Imperato of Watkins & Gunn. And as a group of

trustees we went in to see him, we all went, and we just explained what had happened to each one in our group. And it was the first time, really, we'd had any interest from anyone to take on the cause because I think it was seen as such a massive problem.

And when people actually in a group -- I'm sure other people will have felt this -- once you start telling your story to members of the public who don't know anything about it, they actually think you're a bit crazy because they would think: well, you know, why -- this wouldn't -- the Government wouldn't do this, this wouldn't happen. And it has happened.

So it was only by meeting Michael. Michael said: well, they can't have a consultation in England and expect Wales to contribute because Wales is a country in its own right.

MS FRASER BUTLIN: And that consultation was about financial assistance, just so that everyone is understanding -- (overspeaking) --

MS KELLY: To start with, yes, yeah. And we raised funds through CrowdJustice, then we put out an appeal, but the ultimate goal was to get the public inquiry. And from that time onwards, that's how we started getting progress, because, you know, we didn't know how to go about doing that, really, and we needed legal advice

to do that. And it was just a stroke of luck, really, that -- you know, that we started speaking to Michael about it.

MS FRASER BUTLIN: I'm sure if there are further questions arising from that --

MS KELLY: Sorry, I do have something else to say, if that's okay.

The other thing that was fortuitous as well is that I met my friend at the Haemophilia Alliance meetings and, through her, I met her sister, who was an MP at the time, and she is now *[redacted]*. Because of her position, she was able to open doors at the Department of Health. We'd have never been able to get a meeting with, you know, Lord Prior or -- yeah, at the Department of Health. We wouldn't have got to see Sir Chris Wormald, and that was just through *[redacted]*, because obviously we would have just been ignored, so she opened the door. And that was through my friend.

MS FRASER BUTLIN: I want to move on now to issues of financial recompense, and I'm conscious that some of what we've talked about is woven into that so we'll pick different things up.

In terms of Scotland, Bill, we spoke about the announcement by Shona Robison the day after the

Penrose Report. The first step that was then taken was the financial review chaired by Ian Welsh.

MR WRIGHT: Yes.

MS FRASER BUTLIN: And you were part of that group.

MR WRIGHT: Yes.

MS FRASER BUTLIN: You've described several principles being established that you regard as being central to the schemes. Can you tell us what those central principles are.

MR WRIGHT: Well, as Bruce said yesterday, nobody gets any less as a result of that exercise. And I am referring to -- sorry, my memory, I sometimes need to refer to documentation. I'm referring to witness 051. The reason I refer to this is because it sets the context of what happened during the financial review, because the context was set the day after the Penrose Report came out. And there's reference in there -- it seems that the particular official has put words in the mouths of the First Minister.

But basically, they've put -- he's advised ministers that:

"We agree with Mr Wright's observation and that is why we will carry out an immediate commitment to review and improve the financial support schemes on offer to the people affected and their families" --

and this is the important bit -- "to be concluded before World Haemophilia Day in April 2016."

Now, we were very conscious of avoiding drift, so we'd put that idea into Government's mind about time. And I remember having this debate with Dan about, you know, let's set them a target date. Let's not have the sort of ongoing yearly, "Oh, well, we need to review this, we need to review that". And in a sense we were setting ourselves a very tight deadline.

So we wanted people to be involved in this exercise. That was the second principle, that it wasn't just going to be, you know, a bunch of the great and the good, maybe with us tagged on to it. There was a strong representation. Bruce was there, Alice was there. The SIBF, our partner organisation in Scotland, were there.

And it was actually a good exercise, if I can say that.

MS FRASER BUTLIN: Just in terms of the core principles that you felt were central, nobody was worse off.

MR WRIGHT: Yeah.

MS FRASER BUTLIN: And that people were --

MR WRIGHT: Involved.

MS FRASER BUTLIN: -- central and involved.

MR WRIGHT: Yes.
MS FRASER BUTLIN: And part of the involvement of people was a consultation exercise that Haemophilia Scotland were commissioning to undertake.
MR WRIGHT: The Dan roadshow. Our chief executive. He went out and he listened to what people had to say. He went to Aberdeen, Dundee, Inverness, Glasgow, Edinburgh. But the other thing that Dan did that was really important was that -- you know, there are some people who don't actually like talking in a forum like this, so he did one-to-one stuff. Sometimes face-to-face and sometimes on the telephone. And he brought all that stuff back, and that -- that was really constructive. And there were some messages came out of that particular exercise, one of which reinforced the point about -- points about time and points about not being any worse off.

There was a third thing that came through loud and clear from that exercise and this relates to what then was subsequently the review during the clinical review -- that the clinical review came up with. And that was people did not want assessment. They didn't want to have to go through the big rigmarole. If you go through assessment -- and I have personal experience of this -- it takes a very, very long time.

across, as to a certain extent is represented in the minority report. We've moved on from that since in our thinking.

But there was this -- you know, there were these very clear messages coming through. One of the -- on reflection, one of the things that I think we maybe, because of the time imperative that in effect we'd said, that we maybe didn't quite get right was we were still very stuck to the stage 1, stage 2 hepatitis thing. Hands up, you know. And the signals we were getting from Government was that they didn't really want to break that because of what was, at that time, prior to the clinical review, seen as a clinical element in all of this: you can prove somebody has got cirrhosis, they've got, you know, cancer, so on and so forth.

So that was a bit of a shibboleth that we couldn't really knock down.
MS FRASER BUTLIN: I think you've said that there's a second element that you feel the group got wrong in some ways and that was the position of widows?
MR WRIGHT: Well, ah, no. Actually, we fought very hard for widows. But it was stage 1 widows that we let down at that particular point. There was a misunderstanding about stage 1 widows. I'll come on

MS FRASER BUTLIN: I want to pick up assessment with the clinical review in a moment.
MR WRIGHT: Okay.
MS FRASER BUTLIN: But can I just finish off the financial review.

In addition to those principles, can I ask, were there any financial limits or parameters placed on the group in relation to what they could recommend?
MR WRIGHT: No. One of the reasons we wanted to do this was we wanted to do exactly the opposite to what David Cameron had done to us the day before. We wanted to build this from the ground up.

Now, you know, Government has to look at probity and so on and so forth, but at the end of the day, we wanted to say to Government: look, let's look at a scheme -- and we arrived at -- because we'd got completely fed up, we invited Jan Barlow during the financial review to come and present to us. And, I'm afraid, after we received her presentation we decided we definitely didn't want to go down the road of staying with the Alliance House organisations.

So we were really keen that this was a bottom-up exercise, and the minister went for that. And that was so important. To give people the voice. And obviously, there were conflicting messages came

to the percentage business because -- no, we -- I remember there was a point at which, when we were starting to talk figures, that the whole thing was based on a principle of the median wage. We talked around average wages, and we arrived -- Government agreed that £27,000 at that point was the median wage, so the whole scheme was constructed around that.

10,000 added on for those co-infected and there was a figure of a one-off figure for stage 1s. So the widows -- I remember the moment -- I can't remember if it was Bruce or I, when we were saying, well, what's going to happen here? This is something I feel so passionately about because I haven't -- I've sat in widows' houses and they pour out their stories. It's a very intimate experience. And they'll be in tears.

And I remember Bruce and I, between us somehow, the original proposal that I think came from Government was about 50 per cent, and it was either Bruce or I said, "What about 75?" And we didn't have to push too hard. They went for it.

So the scheme was built around that, but the point that I regret was we didn't also make clear that -- the payments to stage 1s at that point. I think we probably should have nailed it. Let's call it a misunderstanding.

MS FRASER BUTLIN: You then appeared before the Scottish Parliament's Health Committee on 9 February 2016 and that address -- that issue was addressed at that point. Is that right?

MR WRIGHT: Yeah, I was pushing the committee pretty hard not to delay anything, let's not get into party politics here, let's get this money -- I've -- money in the pocket is the thing that matters. We can wait another two, three, four years after this Inquiry, and, you know, how many people are going to be left? So I wanted to get money into people's bank accounts.

If I can illustrate this -- time was moving on, we'd presented the financial report. There's a bit in between here. We presented the report to Government, Government indicated they would accept it in full, but there was a bit in between. We were getting a bit close to World Haemophilia Day.

In the meantime, there was a man dying and, my God, that was hard, because he was one of -- I need to be very careful here because I'm conscious of protecting the family. But he was one of, let's just say, a family of brothers and he'd been through hell and we thought he'd made it: transplants, Hodgkins, come out the other side, got treatment. And we knew his daughter. His daughter had two severe haemophilia

sons. So we were in contact, you know, with that family, and the daughter texted me. I actually remember about four months earlier, I was on the Isle of Skye when she phoned me and said, "Dad's had a really bad diagnosis". He'd developed -- because of the treatment he'd had during Hodgkins, he'd developed leukaemia.

I remember she phoned me. I couldn't actually believe it at the moment because he'd been so lively. And so she texted me to say "Where are we up to with the financial review?" because he would want to ensure that his widow was looked after. So I got back to her, and I said "Would you allow me to take the wording of that text to the Minister?"

She agreed, and I did, and the Minister agreed. And that's the sort of personal impact that's important in all of these, these personal stories, in that they weren't just seen as cases or figures or statistics. And so I think it's important to bear that in mind in relation to what then happened, because I think the Minister appeared before us that day at the financial -- sorry, at the Health Committee.

MS FRASER BUTLIN: Then I want to move you forwards to the Clinical Review Group in mid-2017 --

MR WRIGHT: Yes.

MS FRASER BUTLIN: -- chaired by David Goldberg.

MR WRIGHT: Yes.

MS FRASER BUTLIN: You were one of the patient representatives on it.

MR WRIGHT: Yes, there was myself, the chief executive of Haemophilia Scotland, and Tommy Leggett, who's the manager of the Scottish Infected Blood Forum. I'd like to place on record, please, that our partner organisation, the Scottish Infected Blood Forum, Tommy -- I can't remember if at that time he was paid, but he still continues to be the manager but he does it on a *pro bono* basis without pay.

MS FRASER BUTLIN: I'm going to pick up issues of funding towards the end of today.

MR WRIGHT: Sorry, yes okay.

MS FRASER BUTLIN: Can we just focus on one particular matter in relation to the clinical review, and that is that you've said in your statement that one of the most difficult issues that you had to address during the Clinical Review Group was the issue of assessment.

MR WRIGHT: Correct.

MS FRASER BUTLIN: What were the difficulties and the issues that were being discussed in the Group about assessment?

MR WRIGHT: Well, we were asked, because we were still in this stage 1/stage 2 situation, we were asked examine the whole situation in relation to those who'd -- who from a clinical -- you know, in a clinical perspective in terms of the liver and hepatitis, had not gone on to transplant, carcinoma, cirrhosis, and there's a big issue there because, as I think Bruce indicated yesterday, it's not a simple matter, infects other parts of the body.

However, we were there really to look at the stage 1 situation and the Minister in the terms of reference for the clinical review had specifically asked us to look at this question.

So we started kicking this around, and what was really interesting -- during the financials review, patients had already said, "Don't want assessment". When it came to the clinical review, the clinicians were saying, "We don't want to do assessment", because it affects the relationship between the patient and the -- and their consultants.

Now, there were psychologists, hepatologists, haematologists on that clinical review along with the three of us, and a specialist nurse, and David as chair, as epidemiologist. So it was actually one of the consultants came up with the idea, one of the big

problems we've had in all of this is that patients -- I hate the word "victims" -- but victims have never been trusted so why not let's give this back, why not let them assess themselves? We thought: the Government's never going to swallow that. And it was unanimous: let's go for it.

I've still got an outstanding bet with the manager of the Scottish Infected Blood Forum about how the proportions were going to break down. I think I owe him lunch.

But what then happened was we put it back, people were able -- you know, are you severely affected, are you moderately affected, or -- on a day-to-day type basis it's not really affecting you? And Government accepted the report.

MS FRASER BUTLIN: And, as you say, those recommendations were accepted by the Scottish Government, and so the position, as the Inquiry has heard from previous evidence, is of self-declaration.

Lynne, picking up the position in Wales, can we go all the way pack to 2013, 2014, in relation to the Macfarlane Trust. Your statement talks about the fact that you gathered information about the difficulties people were having with the Trust. Can you tell us a little bit about what those difficulties were?

MS KELLY: Well, they basically couldn't get any money out of the Trust. People would ring and the calls wouldn't be returned. They were asking for support, but there would always be a really lengthy grant process. People weren't given guidelines of what they could -- and could apply for, and basically there was just no money coming forward. And that was a major issue. Those experiences had been combined with -- we'd had a review of care, and obviously grouped in with care is obviously financial support. And we just had lots and lots of patients' experiences about the whole -- about the whole issue.

So obviously I'd -- you know, I would just -- the people that came to the meetings, at the Cross Party Group meetings, they'd talked about their personal experiences. There was then the debate in Parliament, where the experiences were the same wherever you lived.

And we just felt, well, it was difficult because we didn't really want to engage with the schemes because we didn't believe in the schemes. We knew they'd been set up to give as little as possible to people. And we knew a large part of our group weren't included.

So it was a difficult situation. Obviously it

was set up in that way to divide the community, because if you're in a meeting with a lot of people and there would be maybe 30 or 40 people in a meeting at the Welsh Assembly and you've got parents of children, you know, and children, adult children who lost their parents. Once you start getting into detail about schemes and stage 1s and stage 2s and -- it becomes an impossible meeting. So we had to think of a way forward where we would stay as group, and we wouldn't really get into all the details of the schemes. We obviously knew what was going on in Scotland and we knew that, you know, the widows were included, but that wasn't the whole answer.

You know, again, we looked to a wider settlement which was the Irish settlement, and we just felt that that would address all the issues that people in a room were having. We felt, well, that scheme, it wasn't -- it was the best we knew of. We didn't know of anything that was better than that. And you could sort of pinpoint the issues people were having, and you'd think: ah, well, if they were under the Irish scheme, you know, that would work, that could work. So we were really reticent to get into the detail. But we were sort of forced into that position then. And it's as if, that's -- when you come to meetings in

Parliament, then you'll get maybe a minister or a politician thinking: oh, you just want this, a better deal than, you know, the next scheme. But the schemes were all wrong anyway.

So we sort of avoided that, and we just thought well, as a group, people told us they weren't interested in tweaks to the schemes; they wanted the truth. They wanted the truth. They wanted to know what had happened to their loved one. You know, they wanted justice. And they wanted compensation, because, you know, they were entitled to compensation. And everybody knew it. Everybody in our group knew that, and they knew how wrong they'd been. So there was a reticence to try to push for a better -- an increase on a stage 1 or a stage 2, because it was very divisive by nature and we had to -- like, we're small, but we had to keep our group together. You know, we represent -- like, there's 300 people, and we thought, well, we're not funded by Government, we can do what we want as a charity. We're representing the interests of our people, and they're telling us what they want.

You know, and people -- if it was a meeting like that, they could put their hand up and they can say whatever they want and we're not beholden to

Government because we're relying on them for funding. So it was just a last, desperate attempt to get -- try and get the right thing for the community.

MS FRASER BUTLIN: In terms of the Macfarlane Trust, when the monies were being transferred to the Terrence Higgins Trust.

MS KELLY: Yes.

MS FRASER BUTLIN: You lobbied against that.

MS KELLY: I did, yes.

MS FRASER BUTLIN: What was your concern?

MS KELLY: Well, we -- I attended most -- well, all of the Cross Party, All Party Group meetings in Westminster, and the concern was, particularly by our Welsh group that we already had -- we had the different scheme by that time. We already had the Wales Infected Blood Support Scheme, so sort of going back a stage, we -- obviously, we were heavily involved in the Wales Infected Blood Support Scheme and we fed our concerns into Welsh Government and they tried to set up a more holistic approach. So we felt we'd -- they'd sort of listened in that regard but there wasn't enough money in the scheme, so, you know, it could never work properly.

But as regards the Macfarlane Trust, we just thought, well, we just wanted it to do all the things

that the other trusts weren't doing, Macfarlane, Skipton and what have you. But there was a particular issue with the Welsh people, you know, the infected, the HIV infected community, because they weren't consulted about it, they had no input into it.

I would go to the All Party Groups and I'd make it clear that we didn't want the money to go into the Terence Higgins Trust. People, they were just really deeply offended by that, and we asked that the money be divided. We understand that they didn't have psychological support in England, which we had in Wales, but we just said: "Well, why can't the Welsh beneficiaries just have their share of the reserves that are left?" And that -- I voiced that, you know, at lots of APPG meetings. Jackie Doyle-Price attended one of the meetings as well. But it just was ignored.

And then the next thing, we weren't told, but the money had gone to the Terrence Higgins Trust. I then started to engage with the Terrence Higgins Trust, and I think I've spoken to three separate administrators who were administering the fund and basically they're doing another -- they're assessing need, is what they told me. And I said, "Well, are you providing grants? Because in Wales people would prefer to have grants."

"Oh, no, we're just providing services, and counselling services."

Great, you know, if you don't have counselling, that's good. But in Wales we already had psychological support, we had welfare and benefits advice. We'd already got that under the Wales Infected Blood Support Scheme. So we thought it was really unfair that, you know, the HIV infected, why they didn't get their proportion of that.

So, again, it was one of those issues where we felt in Wales that, as involved as I was, my voice wasn't being heard. And I felt that we that the support of our group. We'd asked our group what they wanted, what did they want to do. All the replies came back: they didn't -- you know, they didn't want it going to the Terrence Higgins Trust. And our worry was that the money would be used on various administrators and there wouldn't be any money left anyway. So it was just one of those examples again where -- you know, as a small charity, like, we're all volunteers. I run the charity from my home. But we have a really good understanding of our members in our group and we knew -- like, at a meeting I can say, "This is what our group want". And we don't have other groups in Wales. We don't have any other

campaigning groups. You know, we represent everybody who has had infected blood or blood products, families, bereaved families, and we pretty much thought, well, we can say what we like. We can say what we want to say. And that's the voice of all the people in Wales that can't come up to these meetings.

You know, I'm trying to speak for them, but I just felt that I was ignored.

MS FRASER BUTLIN: You had a particular query about something called the Honeycombe Fund and the Wilson Fund --

MS KELLY: Yes.

MS FRASER BUTLIN: -- and where they'd gone. What were your concerns about those?

MS KELLY: Well, they were legacies that had been set up and they were specifically for HIV widows, so that they could retrain to -- well, I wouldn't like to use the phrase, I think it was used during the evidence, to move on, then, but to train -- you know, to have courses or training to get back to work. And when I asked questions about that, at the All Party Group meeting, you know, other people would say, "Oh, yeah, I might have heard of it", but it wasn't really very well known. This came from some of the older widows who remembered the very early days of the Macfarlane

Trust.

So we asked: well, when the Macfarlane Trust most wound up, where did that money go? You know, where was the Wilson Fund and the Honeycombe Legacy? And basically I don't think anybody knew where it had gone. So I contacted Welsh Government, Department of Health official there, and asked her to -- if she could find out what had happened. But the reply came back from the Department that the Macfarlane Trust was a charity and they had no influence over where that money went. So we are still trying to find out about that.

The other issue we had with the Macfarlane Trust was the fact that they transferred all the data to Russell-Cooke Solicitors, but we didn't know about that. That came, you know -- and there were people then coming forward. They'd heard about the Inquiry, and that they couldn't access their data, and we were just told, well, you know, that's what happened to them.

I did speak to them and, you know, the solicitor there was very helpful but again, it's one of these officials who doesn't know anything about the background, about what has happened. They've just put it in. It's like another new system of -- you know,

just making it more and more difficult, really, for people to get any information from.

MS FRASER BUTLIN: In terms of financial support for hepatitis C, in your statement you said that Haemophilia Wales has been instrumental in maintaining pressure for adequate financial support. Starting in 2016 --

MS KELLY: Right.

MS FRASER BUTLIN: -- there was a consultation running about infected blood support. Who did you understand that consultation applied to?

MS KELLY: Well, we didn't know, basically. We assumed when the Department of Health, you know, started the consultation, it was like -- it was for the whole of the UK. And then you're sort of in this dilemma, well, if you advise people not to engage with it, they're not going to have their views known. And, again, that's how we went, you know, we sought legal advice on that because we really didn't know what was happening. Once -- you know, once the apology had been made by David Cameron, and then there was the other announcement where they said, well, you know, the schemes were going to be the responsibility of the devolved powers, we didn't really know.

So it was -- our lawyers then said, well, we

need to have a Wales-specific consultation.

MS FRASER BUTLIN: Just before we get to the Wales-specific consultation, can we look at the response that Haemophilia Wales did to the English consultation?

MS KELLY: Right.

MS FRASER BUTLIN: WITN3988008, page 2, please, Soumik. Thank you.

We can see at the top of the page, it says, "Response to Department of Health Proposals and Consultation Infected Blood 21st January 2016 England only.

"The proposed scheme is for England only. Welsh affected people have been asked to complete the consultation questionnaire by Carwyn Jones and Mark Drakeford but the proposals do not apply to Wales.

"The Proposals for England do not provide either the infected or the affected with a basic level of financial security. No one will be better off and many claimants will be worse off."

Then if we carry on to page 4, please. In the second paragraph, very pithily in your response, you've said:

"As these proposals are totally inadequate we believe the Welsh [Government] should commit to doing

something better in Wales."

That was your position in relation to the -- if I can call it the English consultation. How had you reached the understanding that it was England only?

MS KELLY: It was from the advice from our lawyers because obviously we were a devolved power, you know, we had our own Government. And that we needed to challenge Welsh Government to do more.

MS FRASER BUTLIN: You then had a meeting with Vaughan Gething on 6 July 2016 and we've got a letter following up from that meeting, that's dated August. Before we get to the letter, can you tell us what that meeting was about? What happened at that meeting?

MS KELLY: Can you remind me?

MS FRASER BUTLIN: Of course, we can go to it, that's fine. It wasn't meant to be a memory exercise WITN3988009.

MS KELLY: Sorry, there's so many -- (overspeaking) --

MS FRASER BUTLIN: If we could have page 2, please, Soumik.

Two particular paragraphs. The second paragraph from Vaughan Gething:

"I appreciated you conveying the community's views about the consultations and surveys that have taken place over a number of years; recent

announcements about reform in Scotland; and likely implications for those in Wales if the England reform proposals were adopted."

Then skipping a paragraph:

"I appreciate you were concerned about the mixed messages you were receiving about responsibilities for the HIV/hepatitis C schemes. I am pleased to advise that the Department of Health has now confirmed it will continue to fund payments for the current Spending Review Period ..."

That, I don't think, can be right, the date that's given there:

"... and that future arrangements will be determined as part of the subsequent Spending Review."

It references a meeting on 6 July. Do you recall what was discussed then?

MS KELLY: Yeah, so I think we were just saying that people in Wales would be worse off under the new proposals, and if Wales were going to implement that, they were doing the wrong thing. That -- I think they basically, in England, they'd said that the widows could have a £10,000 one-off payment, which we thought was disgusting, and we just asked could something more be done.

I think that's when they decided that they would

have the workshops and consultations in Wales.

MS FRASER BUTLIN: What can you tell us about those?

MS KELLY: Yeah, so what happened, I think we had a few meetings in between this, but basically Welsh Government said that they would want to hear the views, you know, of everybody across Wales. Of course, as a group we already knew -- we knew all the views anyway but they had to have their consultation process. But again, it was a bit like the Alistair Burt survey they did for the -- in England of the UK.

When Alistair Burt did his survey they asked people what they wanted, and one of the main -- one of three was that everybody wanted the statutory inquiry. But the Department of Health then they issued their next bit of the consultation and they took that, that first answer, out of it. So that wasn't even asked.

And the survey we had for Welsh Government was basically just focused on the scheme, you know, the financial support: what can we do better to support you? This sort of thing. But it was good because people had an opportunity then to engage directly with the Welsh Government officials and they were done across Wales so, you know, it was -- that was good.

But there was a feeling within our group that it didn't get to the nitty-gritty of it, you know. But

what came out of it was that people, you know, they needed more support. They needed welfare and benefits advice. There was obviously the problem with the widows who weren't getting any money but it didn't look at the wider picture because none of the -- the rest of the affected community, the children and the parents, they wouldn't have been invited to those consultation meetings and that caused a problem for us because they weren't labelled as beneficiaries. And those people were leading people in our campaign, which made our group very strong. They weren't beneficiaries so they couldn't engage.

So, again, it was that issue where, as the chair of the charity you've got to explain to people, look, we're having these meetings and you can't come. That had never happened before, we'd never done it that way in Wales, we just invited anybody who wanted to come, could come. That was a particular problem and then out of the back of that consultation did come some improvement. They did offer the three-year equivalent payment for widows. But, again, after the three years there was nothing.

So the Welsh widows, you know, they had a little bit more money, but when you think that they're paying off debts and a lot of them have lived in real poverty

for years and years and brought their children up, you know, that money didn't last at all because they were paying off debts that they'd incurred or money they'd borrowed from family.

So we felt Welsh Government, they did listen but, again, the consultation was so narrow. It didn't even touch the surface, really, of what was needed. But out of the back of that, then, the Wales Infected Blood Support Scheme was set up, and as per, you know, issues that were raised during the consultation, psychological support was provided, and also welfare and benefits advice.

So they did try and make it a more holistic scheme. And all the issues people had had with the previous Alliance House trusts like, you know, they couldn't get through, they couldn't talk to people, they had a single point of contact. And, you know, the scheme was set up. There's a hospital, a Velindre Cancer Hospital in Cardiff, and the welfare and benefits advisers there, they're specialists, they worked there previously, but they are part of the Wales Infected Blood Support Scheme, so they're really good at getting, you know, where you have appeals for -- you know, PIP appeals and things like that -- we were really struggling -- well, you know, as

a charity we were really struggling to advise people on that because we're not experts.

But they've got really good support there and that bit of it works well and it is much needed.

The psychological support, we did already have psychological support in Wales. Am I okay to go on?

MS FRASER BUTLIN: Yeah, of course.

MS KELLY: Yeah, we did already have psychological support in Wales and that was as a result of the 2011 Task and Finish Group review. And that review was -- we took part in that, but basically it was a multi-disciplinary input then to the review and, even though the number 1 concern for the patients was the hepatology, what came out of the back of it was that psychological support was provided.

So we already had four psychologists should been appointed in 2011, and they were in the Haemophilia Centres but that didn't then -- that was of no consequence to the people who had had transfusions. So they hadn't had any psychological support. So that was included in the Wales Infected Blood Support Scheme.

And that works well, because if families -- if they're haemophiliacs, they can go to the Centre if, you know, they're affected or infected by contaminated

blood and we did make sure of that in 2011, that the haemophilia psychological support wasn't just for the infected person, it was for the affected family, as well, and anybody can access that. Bereaved families as well. And we wanted to make sure that that happened with the Wales Infected Blood Support Scheme. And there are some families who would just find it too upsetting to go back to the Haemophilia Centre. So that works well, that it's somewhere -- it's in another hospital.

And, you know, the feedback I get is the advisers, you know, they're very good and they offer the right approach, and people feel that they can speak to them openly, and they do help, you know, with regards to benefits and the things that we were really struggling to do as a charity.

MS FRASER BUTLIN: So that holistic approach, that side of it, from what you say, seems to be working well.

MS KELLY: Yes.

MS FRASER BUTLIN: In terms of the financial side, some campaigners in Wales were seeking -- or some campaigners were seeking the introduction of a Special Category Mechanism in Wales. Haemophilia Wales wasn't in support of that. Can you tell us why that was? What were your concerns about a Special Category

Mechanism?

MS KELLY: One of our trustees is under the English scheme because of this silly, um -- well, what would -- I don't know why it happens like that. When they made these schemes devolved, obviously it was the country of infection. So he lives in Wales now and he's a trustee of Haemophilia Wales but he was infected in England, so he comes under the English scheme. So we knew he'd had terrible difficulty proving that he was the -- proving the SCM in England but, to us, he is badly impacted, and we just thought that was wrong.

Because we had -- as part of the haemophilia review in 2011, the Minister, Edwina Hart, she announced that we would have a group in Wales which was called the All Wales Advisory Group on Inherited Bleeding Disorders, which we sit on as Haemophilia Wales, and patients can come and they can relay any issues they have to them. But basically -- I've forgotten the question!

MS FRASER BUTLIN: Oh, I'm sorry. Why you weren't in favour of a Special Category Mechanism.

MS KELLY: Right, yeah, so basically, we -- obviously we were in close contact with the haemophilia doctors and, you know, they're always very helpful and, you know, we work collaboratively with them to make sure

that any issues we have, you know, we try and bring everybody together so everybody is on the same page. And the consultant that was a member of our group, he said that he knew there were difficulties in England with the UKHCDO in England, because they were having to go basically jump through hoops to prove this Special Category Mechanism.

So we decided as a group that it wouldn't be the right thing, just because England had it, why do we want to copy something that isn't working in England? So we asked, we put up a proposal and we thought: well, if we had a panel, and under the Wales Infected Blood Support Scheme and the work I've done at the Welsh Assembly with hepatitis C elimination, and there are really good hepatologists on that group and they're very nice and very approachable, and we had this idea that maybe they could be, sort of, a panel and if somebody felt they were more impacted than stage 1, they could go and they could relay their concerns and it would be done in a very nice way. It wouldn't be bureaucratic.

So that was one proposal. And then, obviously, there was the self-assessment where people would -- if they felt they were more impacted psychologically, they could relay that as well, and then out of the

back of that, Welsh Government game up with a better proposal which was that people could self-assess to get an enhanced payment, and we looked at the form, and we obviously fed into it just to make it really simple and it's just three questions, and you don't need medical support in evidence. And anybody who has been infected, you know, they can fill that in themselves. They don't have to tell anybody and then, obviously, they can apply for the higher payment.

MS FRASER BUTLIN: That's the scheme that's been in place for those needing additional support?

MS KELLY: Yes, yeah. But, as I say again, it was about speaking to the doctors who were having -- who would have that additional workload then, to go through all the -- you know, the applicants. And obviously the Haemophilia Centres, they could do it, but then when you've got a transfusion person, they don't have any direct contact with a multi-disciplinary team because often they're not even being monitored if they're stage 1, which is a real problem. And that does need to be addressed, that these people are stage 1, they've had the new treatments, after a huge battle, but they need ongoing monitoring and support. But they don't have access back in -- they have to start with their GP again. And the GP will say "Oh, you

don't need it because you've had the treatment".

MS FRASER BUTLIN: So there's nobody who could write that clinical letter, is that --

MS KELLY: Yeah, there's no -- there isn't anybody. So it's harder for transfusion people because they are completely -- you know, they're not even part of, you know, a haemophilia cohort then.

MS FRASER BUTLIN: Simon, if I can pick up with you. You started lobbying and campaigning in relation to financial recompense, I think, in about 2015.

MR HAMILTON: Yes.

MS FRASER BUTLIN: After the English consultation was announced, you wrote to the leader of the DUP in Westminster, Nigel Dodds. Go ahead.

MR HAMILTON: Sorry, yes, I did. There was a large block of DUP MPs and, as a consequence, my original idea was to try to communicate with as many constituency MPs as possible, and I did, and there were a number of those from other parties as well who were on the APPG. And they were very helpful in raising issues and generally discussing issues within that Westminster community, not only of the Northern Ireland Westminster MPs but of sharing discussion with others, and anything which raised the issue in relation to Northern Ireland was important.

Remember the situation for us was, up until 1998, we had direct rule and then we had a very sporadic and broken system until we got to 2017 when it fully collapsed under HRI, and then we were back in full -- well, effectively direct rule but it was direct rule from a distance, if you like, almost by proxy. And that has only come -- that has only changed again. And during that period, during the -- a couple of sittings of Government, the block -- the majority block of the DUP MPs had a greater significance of influence, and therefore we felt it would be useful to communicate with them and try and get them to highlight the issues that we had as a community of sufferers in Northern Ireland, in relation to payment schemes, because we were watching schemes changing and we were watching schemes varying, and there was an anxiety that we would be left behind once more, in that situation.

So that was the main purpose, to try to keep us at the forefront.

MS FRASER BUTLIN: You received a reply. We have that.

WITN2339018, please, Soumik. If we could have page 2, please.

In the first two paragraphs we can see that he thanks you for your recent letter about the English

consultation, and says:

"I have noted your concerns and will bear them in mind if and when the matter is raised in Parliament. However, health in Northern Ireland is a devolved matter and comes under the [it says remind, I think it probably means remit] of the Department of Health here. Any changes to health schemes in England does not mean there will be automatic changes to any such schemes in Northern Ireland as that would be a matter for our Minister for Health to decide on."

MR HAMILTON: Yes, well, we can untangle the semantics of that in reality because effectively I have submitted other letters for evidence where it indicates also that there was a reference back to the Minister of Health in Northern Ireland.

MS FRASER BUTLIN: We're absolutely going to come back to that in a moment, Simon. If we can just take it in stages.

MR HAMILTON: Sorry?

MS FRASER BUTLIN: In terms of this letter, what was your feeling when you received it?

MR HAMILTON: Well, I was less than enamoured. Effectively, I knew that in reality the Department of Health in Northern Ireland looked over its shoulder at England in order to get its guidance, and that had

been a traditional system within the Civil Service because we had so many years of direct rule. So I was rather sceptical of that and saw it as the beginning of a process of delay. Now I'm sure the minister -- I'm sure Mr Dodds meant very well, and was trying to be helpful but the reality was something else.

MS FRASER BUTLIN: And so you wrote to Margaret Ritchie raising concerns and she made representations to the Department of Health.

MR HAMILTON: She did, yes. She did indeed. And of course, there was reference back to members of the constituency parties who were in the Assembly. But the reality of all of that was that it was actually Central Government that made decisions and was the guiding instrument for even our own department in terms of the treatment and payment schemes and support for haemophiliacs and infected and affected.

MS FRASER BUTLIN: And we've got the reply from the Department of Health, if we could put that up, please, Soumik. WITN2339020.

If we can pick up the second and third paragraphs, please.

"We have acknowledged that while the existing ex-gratia schemes of support have made a significant difference to the lives of many beneficiaries, many

people remain unhappy with the current system of financial and other support. Reforming the current payment schemes remains a priority and we are keen to get this right for those affected.

"The consultation seeks views on providing discretionary payments for travel and accommodation costs relating to ill health. However, the scheme bodies have always been clear that any discretionary payments they have made to registrants of the schemes will not necessarily continue to be made in the future."

And then, at the end of the document, you're referred to the consultation document, and encouraged to provide responses.

MR HAMILTON: Yes, I --

MS FRASER BUTLIN: What was your view of this response?

MR HAMILTON: Unsurprising. Unsurprising. And representative of the general approach, that we were being kept at arm's length. And effectively we were being -- we were being kept under control. I found it insulting, and so did a lot of my fellow sufferers, when we were told that this was something which may not necessarily continue in the future, considering the fact that the needs and also the health needs and the welfare needs of a number of sufferers would

continue regardless of that. And therefore, that in itself was an unsatisfactory answer with an unsatisfactory conclusion.

MS FRASER BUTLIN: And in terms of how valuable your response to any consultation would be, you also received a letter, a response from Sylvia Hermon MP. If we could have that, WITN2339021.

MR HAMILTON: Yes, Lady Sylvia was on the APPG for a period of time and therefore she was well informed.

MS FRASER BUTLIN: She refers to a letter from Simon Hamilton MLA which you've not been able to trace at this stage --

MR HAMILTON: Yes.

MS FRASER BUTLIN: -- but which we will hopefully track down. We can see that she is providing you with a copy of his letter but she also quotes part of his reply. In the third paragraph:

"You will note, however, he has stated in his reply that ... 'The consultation is an opportunity for all those who have been affected to express their views and although the proposals in the consultation paper are for England only, all UK patients have been invited to respond'."

MR HAMILTON: Yes. Well, as I said earlier, that is indicative of -- if it's read carefully by people like

myself, that's indicative of a message which says that what happens in England will ultimately happen in Northern Ireland, and therefore it was essential that we should respond to that under the circumstances.

MS FRASER BUTLIN: And if we go to the bottom we can see that in fact she has put a PS in handwriting:

"Please do submit comments as part of the consultation."

MR HAMILTON: Yes, indeed. And we did. Lady Sylvia has been very helpful.

MS FRASER BUTLIN: In trying to navigate this question of an English consultation, where you were being asked to respond, how did you understand what was going on?

MR HAMILTON: Well, this was really a way of gathering further information from a broader field of people. But the decision-making process was going to be Anglocentric. And if there was a follow-up, it would be the template in England that our Department of Health would address, would respond to. So, from that point of view, if you, if you like, the blueprint would be an English blueprint and then we would follow from that.

And that's indicative of the letter response I got from Simon Hamilton MLA, who was the Department of Health's minister, the one that you referred to

earlier. That would have been indicative of his response, where he really said: we take our direction from the Department of Health in England in relation to support mechanisms.

MS FRASER BUTLIN: So how valuable did you think your contribution from Northern Ireland was going to be to that consultation?

MR HAMILTON: Well, I wouldn't flatter myself. I think at the end of the day the Government had to make this, as far as they could, a public responsive document, and they were trying to gather and garner information. But I don't think, at the end of the day, any contribution we would make would have necessarily had any significant value in that, unless it was being delivered directly through our own system of Government in Northern Ireland.

MS FRASER BUTLIN: Subsequently you received a call from Julian Smith MP, what can you tell us about that?

MR HAMILTON: That was from -- Julian Smith was -- in January '20, he was still the Secretary of State for Northern Ireland. And this came on the heels of a lot of work that I'd been doing, and some of my colleagues had been doing, to try to promote issues around the parity of schemes of payment, so that Northern Ireland wasn't being left behind.

MS FRASER BUTLIN: Simon, that's my misreading of your statement. Then let us come back to it, if it is January '20. I had picked up that it was rather earlier. Let's take it in sequence. My fault.

MR HAMILTON: Yeah.

MS FRASER BUTLIN: Could we pick up then on 22 January 2019 at Portcullis House.

MR HAMILTON: Yes.

MS FRASER BUTLIN: You attended a meeting with a number of representatives from a number of campaign groups, meeting David Lidington and Jackie Doyle-Price.

MR HAMILTON: Yes.

MS FRASER BUTLIN: You've said in your statement that a figure of £55 million was said to be the roundabout figure which would resolve the parity issue. Do you know where that figure came from?

MR HAMILTON: Well, yeah, I know that we had made -- as a group, that -- Bill was involved in that, in that meeting, and Lynne had a colleague in that meeting, so they'll be both familiar with the circumstances. And this -- the meeting came about as a consequence of a number of correspondences between Sir Brian and David Lidington when a request was made that the Government would be responsive to issues around need, and support for sufferers across the United Kingdom.

So obviously the campaign group who were invited to that meeting in Portcullis House included representatives from a number of the campaign groups across the United Kingdom.

And forgive me, I've --

MS FRASER BUTLIN: I was asking you quite a specific question about the figure of £55 million.

MR HAMILTON: Oh, sorry, yes.

At the meeting I noted from where I was sitting that David Lidington sat very quietly, listening very carefully to everything that was being said but didn't spend much time for eyeservice with anybody else. As a consequence, he was playing -- or he was writing down and making notes, and the only comment he made at the end of the meeting was, "How much is this going to cost?" And we had done some calculations and we had actually proposed what we felt was a fair and reasonable solution to the financial issues that were being raised by us, and that figure was roughly a figure which was being presented.

MS FRASER BUTLIN: So that figure was presented by the campaign groups?

MR HAMILTON: It was, yes.

MS FRASER BUTLIN: In terms of Northern Ireland specifically, you had some meetings with Sue Gray,

Permanent Secretary for Northern Ireland's department of finance.

MR HAMILTON: I did, yes.

MS FRASER BUTLIN: What can you tell us about them?

MR HAMILTON: Well, Sue Gray was senior sponsoring officer of the public inquiry at the time. She was also -- had also moved to Northern Ireland as the Permanent Secretary for finance. And after that particular meeting, I happened to meet her in the airport when we were both travelling back and we had a conversation and she said that she had been very positive about the meeting, as had other civil servants at the time, and she suggested we meet again. So we had an opportunity for a couple of further meetings. And Sue Gray was very positive about -- and very, very clear on the need for a resolution to the parity issues as soon as possible.

So I found her very encouraging in that regard. It wasn't -- she was actually a breath of fresh air, because, in a sense, the body of the Civil Service tended to be slow moving and reluctant to accept that there was a need to acknowledge the issues that we were raising, that would have been addressed and dealt with in a simple way through -- initially anyway through a form of financial parity. But she had

a very clear, positive prospective and was quite lateral thinking in how we should -- you know, how things should go.

So from her I gained a lot of encouragement to proceed because she didn't sound -- she didn't put me off, you know, in the sense that she could see around the corner, whereas other civil servants that I did encounter were quite reluctant to move at all.

MS FRASER BUTLIN: Was there an additional benefit in your conversations with her, by virtue of her role as Permanent Secretary for the Department of Finance? Did that give an additional assistance to, or importance to, your contact with her?

MR HAMILTON: Well, I, in no way, tried to exploit her position because I respected her position but, beyond that, she facilitated a number of meetings and, in her role as Permanent Secretary for Finance, she was bringing her awareness of the situation around the contaminated blood issues and issues around parity. And, therefore, when issues of parity equivalence, ie the payment schemes being uplifted, was being addressed -- were being addressed, she was in a prime position to indicate to the Finance Minister, Conor Murphy, that this was something that was potentially worthy.

servants who contacted me a few hours before the moratorium was lifted on the document, and thanked me on his behalf for my contribution. But my contribution was representative of a lot of people's so I would share that with many other people in Northern Ireland.

However, interestingly enough, within that document, at the very end of a series of agreements or commitments on page 9, under the title "Delivering a fair and compassionate society", and that's relates back to what Bill had been talking about earlier on, in regards to the Mace: compassion. The issue of compassion has been represented or recognised here. Under section 9 there was a commitment to provide parity with the English scheme.

And that was a sense for us of real victory. Regardless of what that meant, it meant that Government was finally in Northern Ireland recognising the importance of addressing this issue, and that would -- I would say could be interpreted partially on moral grounds. And I say that now because, having listened to Minister Swann a few weeks ago where he acknowledged the moral issue, and others, the moral battle has already been won, in terms of addressing the needs and issues of victims within this process.

Now, I would say, as well, that there was the new document -- the new document, the new agreement, which spawned the parity -- and you maybe wanting to go on to that but, nevertheless, she would have had an input into that as others did.

MS FRASER BUTLIN: Perhaps you can --

MR HAMILTON: -- (overspeaking) --

MS FRASER BUTLIN: Simon, do take us on to that, that's exactly where I'm going, about how parity and your work on parity has happened.

MR HAMILTON: Yes, really, and a lot of the evidence I've submitted relates to the years 19 -- 2019 and 2020, when we were moving from a position in Northern Ireland of having no Government, to a position of having our Government back. And the new -- the NDNA document was an agreement document brought together by all the parties, under Julian Smith and Steven Coveny in the Republic of Ireland, and that document enabled the parties to move forward. And it was a series of agreements and negotiated arrangements, and within that, issues that we had been very strongly advocating and lobbying for, ie a parity scheme, those were raised.

I did -- as you referred to earlier, I did hear from Julian Smith's, one of his advisers, civil

So that has been contributory to that.

MS FRASER BUTLIN: Before we move on from January 2020 into the present day, I just want to pause and explore with you, what were the difficulties that you faced, given the political vacuum and the collapse of the political situation?

MR HAMILTON: It's a very pertinent question. The reality is -- and I know from other aspects of my professional life -- that the Civil Service in Northern Ireland asks a question with doubt if it has to pay money out. And if there's a sense that there's a profit in this for someone other than the Department, they would be very reluctant to do it.

And that was part of the stalling mechanism we experienced during the period of suspension of the Northern Ireland Assembly. There was an acting Civil Service. The Permanent Secretaries of the Civil Service had power to make decision, but there had been a number of legal cases against decisions they made when significant amounts of finance were spent. And, as a consequence of that, they had been -- they'd lost their power and they realised that there was a difficulty in making financial decisions. So we were immediately up against it in trying to promote the idea and trying to advocate for the idea of the

parity scheme, and we were aware that lots of meetings were taking place and very little was happening.

The other issue, in answer to your question, is this: and that is one of the big problems we found with the Civil Service, that I found and colleagues found with the Civil Service here, and perhaps it spreads across Government in general, and that is that -- and Bill has referred to it and Lynne has referred to it in their experience as well, and that is that sometimes there is a reluctance to be transparent or a reluctance to explain the process. By keeping us in the dark, we are not helped. By keeping us in the dark over this period, many people became quite disillusioned, very distressed, despairing, losing confidence and faith in a system which is supposed to protect them and, therefore, that's not good for their mental health or anything else either.

So there were negative impacts during this period. I found the prevarication, the obfuscations, the delaying tactics, the fear that this was going to spring to another consultation and then another consultation, until we were consultation exhausted before anyone could make a decision. So we were left really in the wilderness until the Minister was

appointed.

MS FRASER BUTLIN: If we can pick up there when the Minister was appointed. You had a meeting with Robin Swann on 13 February 2020, and he wrote a letter to Mervyn Storey MLA, recording what happened at that meeting. If we can put that up on the screen, WITN2339034, please, Soumik. Could I have page 2.

We can see at the bottom of this page, the following:

"As you've highlighted in your correspondence, following a January monitoring round allocation of £1.03 million to my Department, I announced on 27 January interim payments for infected beneficiaries of the NI Infected Blood Payment Scheme, ranging between £4,000 and £8,000 per person. These interim payments were intended as an immediate measure to address the hurt caused by the uplift in England and to alleviate the financial hardship that may be endured by those infected and/or affected by contaminated blood."

Then over the page:

"I was not in a position to allocate the full £1.03 [million] at that point as I needed first to consider how to make the best use of the remainder of the monitoring round allocation in addressing the

needs of our beneficiaries. Whilst I welcomed this short-term funding, a non-recurrent allocation of temporary funding towards the end of a financial year is not sufficient to address all the issues sustainably. Consideration needs to be given to how this issue can be sustainably resolved going forward.

"Financial support schemes across the UK vary significantly, and simply replicating the English regular annual payments to those infected may not necessarily best address the needs of our beneficiaries. As well as regular payments to those infected individuals, there are a number of other areas that need to be taken into consideration in any future reform, which would increase the additional costs of the [Northern Ireland] scheme on a recurrent basis."

I think that's what you had discussed with him at your meeting. Is that right?

MR HAMILTON: It is indeed. It is indeed, yes. In fact, colleagues from one of the other groups, campaign groups, their friends and families group, had met with the Permanent Secretary for Health on a previous occasion as part of our lobbying approach, and they had struggled to make progress. And, I have to say, that Government, once we got our Government back and

the commitments in place, and fundamentally, in fairness to Mr Swann, with a Minister who was committed to doing the right thing, progress occurred quite quickly.

What's interesting in this process is the reality about the cost of support and the fact that the budget within Northern Ireland is rather restricted. And I think this is a bigger issue that the Inquiry must take note of because, effectively, while David Lidington found it quite a useful strategy to devolve issues around payment the reality is, and still remains, that the devolved assembly, certainly in Northern Ireland and -- I can't speak for Wales but I'm sure -- I'm aware that Wales are still battling with this too, with Lynne. I'm aware that the money isn't -- isn't in abundance and, therefore, central Government has a responsibility. It's very easy for a Minister to say, "Oh yes, this is definitely a devolved issue, we must respect the devolution -- the system". Quite right, devolved assemblies have their part, very importantly, in managing and administering the health and support mechanisms but because of the way our fiscal operation works in Northern Ireland we may gather taxes, it goes to England, and it comes back. And, therefore, the

Treasury has a key role in moving forward.

If there were a compensationary arrangement at the end of this process, if there were, and it was left under the argument of David Lidington, for example, that it should be left to the devolved assemblies to arrange and make, then it would never happen, and we would be right back to where we started.

MS FRASER BUTLIN: Simon, I'd very much like to pick those points up with all three of you on the panel in a moment but if we can finish the chronology in Northern Ireland --

MR HAMILTON: I'm sorry.

MS FRASER BUTLIN: -- no, not at all -- then we can pick up those general points. 25 March 2020, Robin Swann formally announced that those in Northern Ireland would receive the same payments as those in England, and payments would be made to non-affected widows and widowers.

MR HAMILTON: Yes.

MS FRASER BUTLIN: At that point you still had some concerns. What were they?

MR HAMILTON: Yes, we that some concerns, I must say again, in praise of the Minister, he made a commitment. He was willing to meet us and he also

met the widows and he was filling to respond and he did make a commitment that he would meet the needs of the widows in some way, which he did, and further to that now, we're in a much better position because of the follow through with the current funding uplift, as it's being finalised.

Mr Swann made commitments but those were commitments -- were temporary, if you like. There was a question mark over their longevity and he explained that there was a mechanism that would be required in order for that to happen and he had to do this a certain way. And he explained that in his own evidence recently as well, that he made the interim payment in the short-term, it amounted to over £1 million -- 1.3, I think -- and subsequently, once that had been carried -- had been provided, in further rounds, monetary rounds, which is the way budget is divided and separated in Northern Ireland, that that funding would become established.

And I received a letter from him very recently which also reassured me of that fact outside of the period of the evidence I submitted to you.

MS FRASER BUTLIN: As you say, things have moved on in Northern Ireland and the Inquiry has heard evidence from Mr Swann himself.

MR HAMILTON: Yes.

MS FRASER BUTLIN: He has also provided a statement in response to your statement which, at the time, was critical of him --

MR HAMILTON: Yes.

MS FRASER BUTLIN: -- noting that things have moved on. He's states he's taken considerable steps to communicate openly with beneficiaries and has increased payments and widened eligibility to include the bereaved. He says that work continues at pace with the other UK nations to achieve greater parity of support across the UK for beneficiaries and says he'll be making further announcements in due course.

MR HAMILTON: And I would totally concur with that. That evidence is much more up to date. The reality is we've moved on considerably and I would commend him for the way he has committed himself and the plans he has transparently laid out to us as well.

MS FRASER BUTLIN: In your statement, Simon, you were very pessimistic and said that you now seriously have doubts that effective campaigning and good advocacy will eventually bring about change.

MR HAMILTON: Yes.

MS FRASER BUTLIN: Is that still your view?

MR HAMILTON: I'll refer to that in my closing statement,

if I may.

MS FRASER BUTLIN: Of course.

MR HAMILTON: I think that will be suitable then.

MS FRASER BUTLIN: I won't steal your thunder.

Can I just open the questions to the whole panel to finish off financial recompense before we take a break.

MR WRIGHT: The break, can we bring it forward? I am afraid I've found myself in serious discomfort once again, and very embarrassing. Is that possible?

MS FRASER BUTLIN: Yes.

SIR BRIAN LANGSTAFF: Absolutely possible. We'll take a break, then, until twenty-five to four.

MR WRIGHT: Thank you.

SIR BRIAN LANGSTAFF: Twenty-five to four.

MR WRIGHT: Thank you.

(3.10 pm)

(A short break)

(3.35 pm)

(Proceedings delayed)

(3.39 pm)

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: Just to round off the financial recompense part of today, can I ask all of you what your view is on whether financial recompense should be

a devolved matter. What the advantages and the disadvantages of it, from your perspective, might be.

Simon, I don't know whether you want to start.

MR HAMILTON: I will, yes.

I think I've already outlined my concerns about that, in the sense that money needs to come from central Government. It is morally the responsibility of Government prior to devolution at any stage, central Government, and practical issues relating to healthcare were derived from the core, and I think that issues around finance are tied to that responsibility and it's not a responsibility of the devolved nations.

I believe the money must come from the Treasury and I believe the Government must do that as part of its recognition and acknowledgement of the situation.

The reality is, on the basis of the last couple of years, even if we'd had a minister in prior to that, he would have been or she would have been struggling to find the finances to provide the uplift.

And bear in mind an uplift in Northern Ireland was £1.3 million. Not 45 million, not 33 million, not 23 million. So under those circumstances, it would be meaningless, it would be a meaningless gesture to make it a devolved matter. It would be

senseless.

MS FRASER BUTLIN: What do the others --

MS KELLY: I agree, yeah. I agree entirely with Simon. The money has to come from the Treasury. It shouldn't come out of the Health budget, because of all the additional stress that causes people. And that's often been used by blockers in the Department of Health to say, "Oh, well, you know, this money needs to be used for something else", and people are made to feel that they're begging for money, and that just is -- it's just horrific for people to think that.

And then when they speak to members of the general public who don't understand what's gone on, people think: oh, those people are stealing money from the NHS budget. And they don't get the sympathy they rightly deserve.

MR WRIGHT: I agree with both Simon and Lynne, but I'll qualify it.

When the Scotland Act was passed, who could have thought that there would be a liability on the new Scottish Parliament and the Scottish Parliament -- and this takes me back to my point about how much devolution there was -- prior to 1999?

So I've actually discussed this at quite a high level. And I see my conclusion in all of this, that

the problem going back, was frankly, the Treasury. There's early -- if you look at a statement associated with the Chief Secretary to the Treasury, then -- who is the person responsible for the control of public spending, in other words, they're the person who stops money coming out -- then we need to go to the door of the Treasury.

My qualification is responsiveness and accountability. And that's where we see an advantage in Scotland. You know, it's bloody hard work coming down here to pin down people in power. It's a lot easier to build relationships positively with devolved Government, and therefore, I firmly believe that we need to stick with a responsive Government in Scotland.

One of the questions we were asked during the financial review was: do you want to stick with a sort of charity type -- Lynne talked about the problems of the Macfarlane Trust. One of the problems we had was that we were asked by the minister, "Do you want that sort of arrangement, but with a Scottish set-up, or, do you want a responsive, directly accountable scheme?"

Now, SIBSS is part of, in effect, the Scottish Department of Health. And she was very interested in

that and she backed us, because we made the decision that we wanted to nail people. And when I'm dead and gone, they'll be, you know -- people can be nabbed. And I think that that's an element of this, that we -- what I want to avoid is a situation where there's a ding dong battle between Government in Scotland and Government down south.

So that's my qualification.

But there is clearly an issue in terms of ultimately who pays, and I would very -- one other point that I'd overlooked was when we had the financial review in Scotland, the Scottish Finance Minister in 2016 came up with £20 million from the Health budget in Scotland. Going back to this Susan Deacon attitude -- and I'm sorry, sir, but I think this just illustrates what we've been through -- this is when she's talking about affairs, about --

MS FRASER BUTLIN: Do you want to give me the number of the --

MR WRIGHT: Yeah, 029. Witness 029.

MS FRASER BUTLIN: WITN2287029.

MR WRIGHT: If you go to the page with her picture on.

MS FRASER BUTLIN: It's page 5, Soumik.

SIR BRIAN LANGSTAFF: Have you got it?

MR WRIGHT: Yeah, if we maybe could scroll down, rather

than her teeth.

If you look at the second --

SIR BRIAN LANGSTAFF: I'm not sure everyone has --

MR WRIGHT: Oh, sorry.

SIR BRIAN LANGSTAFF: Thank you.

MR WRIGHT: If you look at the second bottom line there, this was Susan Deacon in -- I mean, let me work this out -- around about 2001, 2002:

"A worse-case scenario (sic) involving compensation to around 400 people might cost us £20m."

It took us 15 years to get there, because of that point of view!

So yes, the money, the money has to come from the Treasury.

MS FRASER BUTLIN: Lynne, Simon, do you have any views on that point of, yes, it comes from the Treasury but there's a qualification?

MR HAMILTON: Sorry, Lynne first.

MS FRASER BUTLIN: Go on, Lynne.

MS KELLY: Yeah, I would say, from our perspective, that we -- at this time, at this moment in time, we wouldn't be able to say that we would want to have any sort of scheme because we've got -- we haven't consulted with our group and that's what we're going

to be doing over the next -- and obviously I've sent out to our members that our next meeting will discuss this very issue. So I don't really -- but definitely the money has to come from the Treasury. It shouldn't be left to the devolved governments.

MS FRASER BUTLIN: Simon, did you want to chip in?

MR HAMILTON: I just make a comment, yes. I think the reality is that the Government cannot pay currently for its responsibilities in Northern Ireland, and they would be looking to Government in England to increase payments that come in so that they could manage their responsibilities. From that point of view, it's illogical that they could possibly deal with this.

In terms of constraints on Government, this is early -- it's early days in terms of how monies would be agreed. Similarly, with Lynne, we were talking to colleagues in relation to how arrangements for compensation might be delivered, and considering different routes for that. So beyond that, at this point, I wouldn't really want to comment.

MS FRASER BUTLIN: I want to move on to two issues. Firstly, a question about look-back in Scotland and then quite a lot on clinical treatment in Wales and also in Scotland and Northern Ireland.

But in relation to the look-back, Bill, there

was a particular series of documents you wanted to raise. So if we could have WITN2287053, please. And if we could have page 5 of it.

What we're looking at is a note of a meeting on 10th February 2000.

In fact, sorry, Soumik, could we have page 2 so we can all see what this meeting was?

We can see at the top:

"Note of [a] meeting ... in SAH to discuss the information required to assist in the examination of circumstances surrounding the safety of SNBTS blood products from hepatitis C."

And if we go on to page 5, please.

MR WRIGHT: Before we do that, could I just point out that the handwritten note, the annotation on the front page about the attendance, is my wife's handwriting.

MS FRASER BUTLIN: If we look on this page we've got paragraph 9, and there's lots of underlining and annotation and I think, as you say, the annotations that your wife's made during the Penrose Inquiry. Is that right?

MR WRIGHT: Yes.

MS FRASER BUTLIN: The paragraph reads:

"Professor Lowe pointed out that most patients would have been infected whilst their predecessors

were in post and asked whether it was necessary to contact them to make them aware of the situation. Mrs Towers explained that this was a factual information gathering exercise but that it should be borne in mind that the information might be used in future Court actions. Professor Ludlam also sought advice on whether [the haemophilia directors] should be looking back to try to identify what had happened to patients whose whereabouts and status were unknown. Mrs Towers confirmed that Central Legal Office was representing the Trusts and SNBTS and that their HDs should therefore follow CLO advice on whether any further investigation or the tracking down of patients was necessary."

In relation to Mrs Towers, do you know who she is? Was?

MR WRIGHT: She was from the solicitors office within Government.

RACHEL: I want to look at the next document and then ask you about the two documents at the same time.

If we can go to WITN2287054.

This is the report of a Scottish Government commissioned short-life working group, published in August 2016. And if we can turn to page -- I think it's probably your page 6, Soumik.

Under the heading "Executive Summary" we see that it says:

"The Penrose Inquiry, published on March 25, 2015, recommended 'that the Scottish Government takes all reasonable steps to offer an HCV test to everyone in Scotland who had a blood transfusion before September 1991 and who has not been tested for HCV'.

"A Short-Life Working Group, established by the Scottish Government, was asked to consider what specific actions should be taken in the context of the Inquiry recommendation."

Then it carries on:

"To assess the extent of the problem -- ie, estimated numbers of living HCV infected individuals who acquired their infection through blood transfusion in the UK pre-1991 and who remain undiagnosed ..."

It then carries on to say that it's estimated that:

"... approximately 100,000 people ..."

If we can go over the page:

"... who received a blood transfusion pre-1991 in Scotland are still alive;

"approximately 100 of those 100,000 (0.1%) are HCV infected;

"around 30 of the 100 remain undiagnosed."

If you bear with me, following through to 2021, WITN2287055.

Page 2, please, Soumik.

We have a Freedom of Information Request which asked:

"With regard to the implementation of the second recommendation of the Penrose Short Life Working Group, you asked for:

"1. How many individuals were traced; and how many couldn't be traced?

"2. How many of those traced were alive and how many had died?"

If we go to the next page, the response. Just under the heading "Response".

"Based on the information we received from Health Protection Scotland in 2018, of 69 patients whose status was investigated as a result of the Short Life Working Group recommendation, 33 patients were traced by CHI linkage analysis, and 36 could not be traced.

"2. Of those traced, 20 were alive and 13 had died."

Bill, you wanted to draw our attention to these documents. Can you tell us what your concerns are, particularly about that first document in relation to

the questions from Professor Ludlam?

MR WRIGHT: This issue has haunted me. And it's, to a certain extent, sir, already partly been addressed by questions to both Professor Ludlam, Professor Lowe, when they gave evidence. But my conclusion is that people, as a consequence of the Central Legal Office's advice, in February 2000, were allowed to die. And it's haunted me, because I went and asked some questions about what had happened. I asked Dan to see if he could follow it up with Government.

We see a number here of 13 had died. We don't know how they died. Now, bear in mind that during the Short Life Working Group, Professor Campbell Tait was asked to go -- not only in the follow-up to the Penrose Inquiry did they look for those who'd been not identified, who'd had a blood transfusion, but Campbell Tait actually went away to look at those who'd been, like myself, a male haemophiliac, where contact had been lost.

Campbell found I think it was 69 names. And, you know, we've got some stats in front of us here. 36 could not be traced. If this exercise had been conducted 15 years before, it would have been a lot easier to find those 36 people and not worry about whether or not they might bring out a lawsuit. You'd

actually treat them, support them, save their lives!

Now I realise that this is a very serious accusation but why on earth were lawyers determining public health decisions? Because we were a walking public health issue. Why were those lawyers -- and remember, this was during the time of Susan Deacon. The Deputy Chief Medical Officer was at that meeting.

The other thing that scares me about this is: where did the power lie at that time? We'd got senior consultants from the haemophilia world, but their lawyers were calling the shots. It's a disgrace, this. It's an absolute -- we talked about this being a public scandal, this is one of the worst scandals that happened in Scotland.

I'm sorry, sir, but I have been very deeply disturbed about this, and this is worthy of very deep investigation. People need to be held to account here. You can't just allow people to wander around and not go and try and find them. The fact that that Short Life Working Group managed to do that exercise 15 years later shows that you can at least make the effort. They didn't make the effort.

I'm sorry, sir, but I -- it's wrong. I'm sorry, Lynne.

MS KELLY: Can I add something to what Bill has just said?

MR WRIGHT: Yeah.
MS KELLY: I've got two points to make. What always concerns me is the fact that this is the 1991 cut-off date and we know there's people in Wales who were infected after 1991, so why is that the cut-off date, and that means that people aren't able to claim support?

The second point is that the point you raise about -- specific to Scotland, my experience is that that is happening in the Department of Health in England. I've been in meetings where they've talked about hepatitis C look-back exercise. I don't think it ever happens and, particularly for the haemophilia cohort, all that would need to happen is the national haemophilia database holds all the data on the patients, the clinic notes at all the Haemophilia Centres would have all the information. We know there was nearly 100 per cent infection rate with hepatitis C, so it would be fairly easy to find those figures for the haemophilia cohort.

Again, more difficult for transfusion, because they are -- you know, they're individuals and they're not part of a cohort.

But my opinion is that the Department of Health and Government don't want to find out how many people

are infected because, if they did, they wouldn't be -- they would just argue that they couldn't pay for it and they couldn't afford it. And yet, at the same time, we go to Parliamentary debates and we hear about these -- the massive figures, the amount it's going to cost compensate all these people. They just pluck a figure out of the air. So they overestimate but they make no attempt to find these people. And, you know, most people, they just die, and it's never recorded.

And, again, it goes on to this issue about why aren't -- why isn't everybody offered a hepatitis C test? Why do people have to go and seek one out? Why have they got the '91 cut-off point? Why don't they just offer it to everybody? Or just a really simple question to the patient: "Have you ever had a blood transfusion?" It's not difficult to ask a patient that.

Some people might have had an operation and they don't know they've had one but, generally, I think most people would know if they'd had a blood transfusion or not. And if they wanted to find the people, they would do that. They don't want to find them, that's the reason why.

MR WRIGHT: I absolutely agree with Lynne here, because

this episode characterises Government's attitude on this whole episode. We've talked about the word "cover-up". This is indicative, this characterises the cover-up.

And these are people. They're not just numbers. They're people. And I think in respect of what Lynne is saying here, you know, this wasn't about them, whether or not they'd qualify for the money and let's get it -- this was about treatment, the NHS, saving people's life.

Lynne's right. In the early days of the Scottish Government, it was still happening.

MS FRASER BUTLIN: Simon --
MR WRIGHT: I'm sorry, sir. This is just horrible.
MS FRASER BUTLIN: Simon, is there anything you want to add?
MR HAMILTON: Yes, again, I think this comes back to the heart of the issue of responsibility, and responsibility is vested in those whom we put our trust in. And obviously, preventative care is also about being prognostic and knowing the scope of what -- of the problems that have to be dealt with in relation to healthcare and health treatment. If the reality is that there is an assumption, an -- a reasonably well-informed assumption, that there is

a bigger problem out there, without actually trying to address it, then that is a mistake, because that bigger problem will be a bigger problem. And a bigger problem is what we want to try to avoid on the back of this Public Inquiry. This is about lessons learned, and lessons learned means that action needs to be taken.

And, in terms of Northern Ireland, I would have relative confidence that, certainly in terms of the infected blood community contaminated haemophiliacs are well protected and well looked after, there's a knowledge of their need and we've got a very good health centre here for haemophiliacs under Dr Benson.

I would have a greater concern in terms of the broader victims, the broader infected contaminated group and how clear Government is about the numbers that that actually entails. And, unless we know, we don't know. And that's is -- saying that makes it simple and clear.

MS FRASER BUTLIN: If I can move on to a different topic. Lynne, a lot of your work over the years has also been in campaigning for the provision of services within Wales. You mentioned the psychological support and the outcome of that, I think, was that there's now four haemophilia psychologists in Cardiff, Swansea and

Bangor. The hepatology provision in Wales has been much more vexed, from your statement.

It's right, isn't it, that from 2007 there was no hepatology care in Wales after the hepatologists left his post --

MS KELLY: In South Wales, yes. In South Wales. Sorry, I need to correct that. I mean, in Cardiff area. Excuse me. There was a hepatologist at Swansea but there wasn't one at Cardiff.

MS FRASER BUTLIN: A Task and Finish Group was established in 2011, to consider haemophilia care in Wales and it reported in June 2011.

Can we look at that. I want to turn to a couple of documents and then I'll ask you about them. WITN3988013, please, Soumik. If we start at page 2, please.

We can see under the heading "Background":

"On the 8th March 2011 the previous Minister for Health and Social Services made a statement about the support available to individuals infected with hepatitis C and/or HIV by NHS supplied blood transfusions or blood products and their dependents. As a result of a commitment made during her statement a Ministerial Task and Finish Group was established under the chairmanship of the Medical Director for NHS

Wales to review services for people with inherited bleeding disorders."

Then we have a heading "Summary of patient concerns" and we can see a number of matters which are underlined but if we carry on over the page, we see as number 8, "Clinical Support Services", and it's noted:

"Gaps in the provision of various Clinical Support Services are apparent. This is most significant with regard to the hepatology service at Cardiff and Vale University Health Board ..."

Then if we carry on to page 5, please, Soumik. We have a heading "Gaps identified by the Task and Finish Group":

"The main gaps in services identified by the Group were:

"Lack of counselling and social work support across Wales

"Lack of hepatology support particularly in Cardiff ..."

We then carry on to page 8, where hepatology is picked up again, where the recommendation is that:

"LHBs through their joint work on WHSSC should

"Ensure appropriate consultant and specialist hepatology nurse input into the treatment of patients with inherited bleeding disorders must be provided in

Cardiff."

Before I ask you about that, Lynne, could we also look at the ministerial announcement, WITN3988014 please, page 2. This was on 1 November 2011, arising from the review, and if we see in the second paragraph:

"The effective management of patients with inherited bleeding disorders is complex and involves the provision of comprehensive care by a team of healthcare professionals with diverse skills. The Group, therefore, considered a range of issues raised by patient groups on the planning and delivery of diagnosis, treatment and support services, including physiotherapy, counselling and social services support, for people with inherited bleeding disorders in Wales."

Then just after that:

"The Review made a number of recommendations. The Welsh Government is providing £96,369 additional funding on a recurrent basis to support counselling services for those with inherited bleeding disorders which was one of the main recommendations contained within the report."

When this ministerial announcement was made, what was said about hepatology?

MS KELLY: Nothing.

MS FRASER BUTLIN: What concerns did that --

MS KELLY: So, obviously, when they talk about patient groups, that's our group, and we know everybody, and we got all the patient experiences together, and the number one concern was access to consultant hepatology opinion.

And when they announced -- so that was -- we obviously -- we work collaboratively with the haemophilia clinicians in Wales and I know -- you know, we know them all, and there were patient representatives as well. And that was the number one concern that was put forward to Government. And when the announcement came, the funding was allocated for psychological support, which was needed, but it wasn't the priority at the time, because the psychological support was already too late because people had already died, and why couldn't those support services have been in place before they died? And maybe they wouldn't have died.

So it could never really resolve that issue and what made our group really cross was the fact that the £96,000 was allocated but we felt that was just in an easy win to put that in the announcement. It looked like Welsh Government were doing the right

thing, and we are grateful for that because, obviously, we did end up with our four psychologists, but there were issues around physiotherapy as well, and obviously we spoke to the haemophilia clinicians and the other members of the Task and Finish Group, gastroenterology lead, and there were all sorts -- all multi-disciplinary input -- haemophilia nurses as well, physios, social workers. And, basically, I don't know whether you're going to show these emails but there are emails in my statement which shows the support that the haemophilia doctors in Wales had for the patients' number one concern, because they knew that it was such a concern.

And the haemophilia doctor, particularly in Cardiff, felt that, you know, it was much needed, and he had made a case for that to the health board, to Cardiff and Vale. But there was -- you know, nothing happen. Basically, they were ignored.

So we had group of haemophilia doctors, the Welsh doctors, they were supporting what the patient group was saying. We documented all the patient experiences. We had various meetings. But basically there was no money, and, unless -- well, we knew that unless Welsh Government allocated funding for it, it would then turn into an argument before -- between

Cardiff and Vale Health Board, and the Commissioners in Wales for haemophilia care, which are Welsh -- they're called Welsh Health Specialist Services Committee, because neither of them would want to fund the appointment.

And the critical thing was that, if they appointed a hepatologist at Cardiff -- at the Heath Hospital in Cardiff, that -- if they weren't -- if it wasn't dedicated for monitoring of haemophilia patients or, better still, monitoring infected blood patients, nobody would want to fill that post because they'd have to do all the general day-to-day gastroenterology duties and emergency. So our group of patients still wouldn't have any benefit out of it.

So the only way it could work is if the funding was specifically allocated for access to consultant hepatology for the infected blood group. And that would mean that they would have a priority access and they would get regular clinic appointments, and they would be monitored, and, you know, that -- it does happen in Cardiff. But I think across the UK it's not happening. And I know people it's -- you know, that's true.

MS FRASER BUTLIN: Your concern was that you didn't want a generalist -- a general gastroenterologist.

MS KELLY: Yes, yeah.

MS FRASER BUTLIN: You were campaigning for a specialist hepatologist --

MS KELLY: Yeah.

MS FRASER BUTLIN: -- to deal specifically in hepatology.

MS KELLY: Yeah, so the clinicians, they all wrote to the Welsh Government, and -- or Dr Chris Jones who was the Deputy Chief Medical Officer, in Wales, voicing their concerns, and they also wrote to the Welsh Commissioners, WHSSC, because we felt that as haemophilia care, the Commissioners in Wales should pay for that, because this is part of haemophilia care. These people didn't just go out in the street and catch these viruses. It should be part of the National Service Specification.

And, basically, the clinicians were ignored. And we just had to go back to lobbying through the Cross Party Group then. And without their intervention, it would have been ignored, we wouldn't have got anywhere. So obviously all our Assembly members started asking questions in the Assembly and putting the Health Minister on the spot.

And, without that, without that collaboration from both the medical profession and the politicians, we would never -- we just wouldn't have got it.

MS FRASER BUTLIN: Ultimately you asked Assembly member Julie Morgan to write to the new Health Minister --

MS KELLY: Yes.

MS FRASER BUTLIN: -- who agreed to reconvene the Task and Finish Group --

MS KELLY: Yes.

MS FRASER BUTLIN: -- just for a single meeting to discuss the implementation of the earlier report. Is that right?

MS KELLY: Yeah, because basically there was no progress, no one was going to pick up the bill for this. Neither the Health Board nor the Commissioners. And, basically, we were just being fobbed off. So we made some very angry representations at one of the group meetings, and Julie agreed that she would start lobbying on our behalf to make sure that the Task and Finish Group recommendations were implemented.

MS FRASER BUTLIN: Ultimately, a gastroenterologist was appointed.

MS KELLY: Yes, after all of that, and after all the clear representations -- as I say, we knew -- the patients know what they want, they know what they need. They are the experts by experience, and they are the people who -- they can -- if you ask any patient, you know, some people are a little bit more reticent but,

basically, when somebody says in a meeting "Oh, I'm having difficulty with this", you'll always get other people, and that gives people confidence then to talk about it. But, basically, we obviously spoke to our clinicians about it and they gave us direction about the sort of post we were looking for, and that was because, you know, we have a good relationship with them, and we want, you know, we want to work to try to get the best for the survivors.

But, basically, they ignored that, to, I suppose, dampen down the, you know, the angry noises then. They said, well, they were appointing a gastroenterologist but, again, this gastroenterologist, he was just up to here with all his general gastroenterology, so he wouldn't have time -- he wouldn't have time to see the haemophilia patients unless it was an absolute emergency and that was the very scenario we wanted to avoid, because we felt that our group of patients, under the circumstances of their infection, they deserved to have that care where they're monitored and they have a comprehensive care package, to avoid people decompensating and not being referred to the appropriate specialist.

If they're under the care of a consultant

hepatologist, they're monitored, there's specialists, they know exactly -- if things start to go wrong, those patients get a chance then, because they -- you know, they can be put forward for liver transplant. Whereas if they're unmonitored, you know, liver disease is called the silent killer and there are lots of people in our group who, you know, maybe outwardly aren't showing many symptoms, but they're -- inside, their liver is failing. And they may go on for years without decompensating, but, you know, it -- very often it'll happen very suddenly and then its an emergency admission, and then it's too late and a cancer has grown and, you know, people just die because of that.

MS FRASER BUTLIN: And there was also some delay in the person joining the Trust because they were doing some further hepatology training and -- (overspeaking) --

MS KELLY: Yeah, and he wasn't -- he wasn't a specialist hepatologist, but we did eventually get our consultant hepatologist then, 2015, Dr Srivastava, he started. And again, he sees the haemophilia clinic patients during clinic time.

We still feel that the stage 1s should be monitored even though they've cleared the virus, they don't have an active virus now. But it's really

important that that monitoring takes place to, you know, to prevent, you know, it being an emergency admission.

And as I say, but that's of no consequence to the transfusion people, because unless they're attending the hospital, the stage 1s will just -- they're just off the radar and they say they're cured. And they're not cured, and they're not called back.

MR WRIGHT: Counsel, might I support what Lynne is saying here. We've got a bit of an obsession in Scotland about care plans, and we've had different experience in relation to hepatology support. In 2006 there was an action plan to eventually rid Scotland of hepatitis C. That's for everyone. And in some parts of Scotland that's almost been achieved.

And now, within the haemophilia community, it's certainly, as far as I'm aware of, if you wanted treatment, you could get hepatology treatment. But the point here that's coming out from this sort of -- what Lynne's talking about, where you've pioneered in Wales in relation to psychological support, you've also got support in terms of benefits. But hepatology hasn't necessarily always been there.

And there are psychological -- you know, psychological support. What we actually -- my

obsession is for a care plan for people who have been affected by this. And in some cases I include families in that. And I see huge benefit in that.

One of the problems we've identified with this, and I think Lynne is touching on it here in relation to blood transfusion, is who would be the lead professional? You know, from which particular field would they come from, in terms of that agreement between the patient and the NHS? Because we know that there are very complex needs and co-morbidities, and it's something that we've been seeking to raise through our network in Scotland, Inherited Bleeding Disorders Network, but as Lynne says, it's about people with blood transfusions as well.

MS FRASER BUTLIN: Just picking up on the network in Scotland, because one of the things you've also been trying to work on is improving the psychology service in Scotland. Differently to Wales, because Wales, you were successful in it. What's happened with Scotland in terms of psychology?

MR WRIGHT: Well, until very recently, Wales were ahead of us. And I think it goes back to the report, the King's Fund throughout Wales, way, way, way back.

We had support for some years now and initially it was on a sort of pilot basis for two or three years

for people with haemophilia. That was extended from the Lothian region across Scotland, but only very, very recently. In fact appointments have just been made within the last couple of weeks for people who are -- either had blood transfusions, who are in a nearby hospital or, in some cases, frankly, families who have lost loved ones, they don't want to go near a haemophilia unit. So that's available to them. But I am aware that there's been close liaison between those two parts.

MS FRASER BUTLIN: And that's been through the Scottish Inherited Blood -- sorry, Scottish Inherited Bleeding Disorders Network?

MR WRIGHT: No, let me clarify here. This is Scottish Government's -- the other pat of it, the non-haemophilia part of it. But I believe the psychologist from the haemophilia world was actually involved in the interview panel for the people with transfusions and families.

MS FRASER BUTLIN: Just staying on psychological support while we're on it, Simon, in relation to Northern Ireland, we heard from Dr Benson that there's been additional psychological support established at the Belfast Centre in the context of this Inquiry. What's your involvement been in relation to that?

MR HAMILTON: Yes, absolutely. I think, really -- and I was listening to what Lynne and Bill were saying. I think really, in terms of dating it, it certainly is something which was post the beginning of the Inquiry. In a sense, I would probably associate that with the terms of reference of the Inquiry. I think there's been a movement by the Belfast Trust to acknowledge issues around mental health.

We have a dedicated psychologist. That post is very shortly going to be made permanent. In fact that date might already have passed, I haven't heard the final result. But I'm aware that that service has been used and utilised and is offered right across the province. Under the pandemic, that process has been promoted through Zoom or Teams, and accessibility continues.

And some of the benefits of that process are that it has enlightened us, really, that there's a need not just in terms of dealing with the traumas that have arisen out of the public Inquiry and contaminated blood, but the general issues of trauma and psychological disturbance which come for families when they have haemophiliacs who have serious bleeds, and serious accidents which occur. And also for individuals as well. So I think there's a realisation

that this service is a service which will have a broader use and a broader usefulness in terms of the patient care and family care for those suffering or within the contaminated -- blood contaminated community. Certainly in terms of haemophilia, and anyone related to the public Inquiry.

In relation to the other issues that were raised earlier on about hepatology and the service itself, I can only speak personally. We haven't had any real anecdotes of people who are not happy with that service. So I can't identify that. I can say in terms of myself, as a stage 2 cirrhosis sufferer, that only the other day I had a phone call asking me to go for a blood test. So that reassures me that even through this process, when it's difficult to access monitoring, monitoring continues. And that's reassuring.

And in terms of my brother, who -- my twin brother, who developed cancer and had a liver transplant, that service delivered him into good health very well. And I hope that is the case for others.

My understanding of any folk that we have come into contact with has been that it has been a reasonable experience.

MS FRASER BUTLIN: Just before we leave the campaigning in relation to clinical issues, Lynne, you were heavily involved in lobbying for access to interferon-free treatments. What response did you get when you raised the question of providing that?

MS KELLY: Right. So that came about because when I was a trustee of The Haemophilia Society, I was asked by -- well, the chair basically couldn't attend a meeting and he asked one of us to attend. And when the email came through, I saw that it was going to be an important meeting and it was in the Department of Health, and it was a hepatitis C workshop.

And the chair of the meeting was Ben Cole, who was somebody that I'd met previously, and who had walked out of meetings when the Haemophilia Alliance was dissolved and nobody would stand up and agree with what I was saying. So I had a bit of a history with him. So I thought, right, I'm going to go to that meeting.

And when I went there, there were presentations from leading hepatologists on the new interferon-free treatment. So this was December 2013.

And basically I spoke to Professor Dusheiko from the Royal Free after the meeting. I obviously spoke at the meeting and said we were having difficulty

because we couldn't even get our patients monitored at that time. And he told me that there had been no input from the infected blood cohort to any of the previous meetings. Which shocked me. There had been input from the Hepatitis C Trust through lived experience, but the person hadn't been infected through contaminated blood. That person had had hepatitis C through other means.

And basically, he said that, "We are trying to -- as hepatologists, we're tying to lobby for an early access scheme", prior to NICE approval.

So I emailed -- he gave me his email address and I emailed him, and he gave me the information which demonstrated that, you know, they were basically lobbying NHS England to pay for these drugs because they knew there was near to a 100% success rate, particularly with the non-responders or the people who hadn't cleared the treatments with three or four previous interferon treatments.

So he sent me the email, and then I contacted one of our Welsh patients who was at the stage where their liver was decompensating and, as a favour, we'd asked for Professor Thursz, who -- I can say the doctor's name? Right, Professor Thursz, who is at Saint Mary's in London, to monitor him. And

Professor Thursz is a leading hepatologist and he kindly agreed to see one of our patients because this man was going to die, basically, if he hadn't been seen, and he didn't want to wait. His brother had already died, so he didn't want to wait to get to the stage where the liver -- the cancer had developed outside the liver.

And Professor Thursz saw him, and when I emailed him, he immediately replied back to me and said -- I think you've got the emails in my evidence -- but he says that we're trying to lobby for early access, and he said, "There's no representation from the infected blood community". He said there's a press conference the next day at the Kings Fund, and he said, "We're trying to push NHS England to pay for these treatments because we know they're working".

So he said, "Would you be able to come?" And myself and a few others from our group, we went up to the Kings Fund, and we spoke about what was happening and, of course, the people there -- you know, we met -- there were obviously all sorts of, you know, people who had been infected by different means, but everybody was really friendly to us, and, you know, they said "Oh, we had no idea that, you know, your group could be infected in that way".

So, basically, I reported -- I -- actually, I reported all of that back to the Haemophilia Society, and I should add that when I went to the workshop, which was chaired by Ben Cole, I did actually ask for Joseph Peatty to come with me because he's got a background in statistics. He's one of the -- oh, can I say his name?

MS FRASER BUTLIN: Can we just pause the transmission just in case. I didn't think it was redacted.

[Pause in transmission]

I don't think the name is mentioned in your statement, so I'm not sure if it is due to be redacted.

SIR BRIAN LANGSTAFF: I think better refer to him neutrally if you can.

MS KELLY: Sorry, can you say that again?

SIR BRIAN LANGSTAFF: If you refer to him neutrally, if you can, rather than by name.

[Pause in transmission]

We're back on.

MS FRASER BUTLIN: Thank you, sir.

MS KELLY: One of the campaigners in England, he had a background in statistics and I knew that he would be able to help me at the meeting, and I asked for him to come, and that was refused. So that's how I went on

my own. And, again, I thought that that was wrong, because there was no other representation at the meeting, apart from the Hepatitis C Trust.

So, basically, we went to the meeting and to the press conference, and we spoke about, you know, how our group were being denied the drugs.

I reported all of this back to The Haemophilia Society because I was a trustee at the time, so if I did anything, I would always have to report it back to the Board. And, you know, to get sort of Board approval to do these things. So I sent an email to the -- to Bernard Manson and Liz Carroll, reporting what I'd found, and I said, "Look we need to be really lobbying Government now to get this moving".

And, basically, they just didn't understand. They didn't understand what the urgency was about. But when you know the people so well, you know them personally, and you know it could save their lives, you think, well, for many that was the only hope they had. And --

MS FRASER BUTLIN: Sorry, sir, we've had a response from Bernard Manson challenging that position and he would say he did understand.

MS KELLY: Right.

MS FRASER BUTLIN: Can I just focus your answer, Lynne,

back on what I was asking about --
MS KELLY: Sorry, yes.
MS FRASER BUTLIN: -- and that was about what you did in relation to lobbying the Welsh Government for access.
MS KELLY: Right, okay. So what I did then was I sort of felt -- I was just blocked, really, in both areas. And so I resigned and I just thought, well, it was easier to not have to report back to The Haemophilia Society that we would do it ourselves in Wales. We already knew all the -- we knew the Welsh Government, we knew the politicians. So through the All-Wales Advisory Group that I sat on, I made a case for -- there were less than ten -- I think it was between six and ten people in Wales at the time who needed the treatment. And, basically, we just appealed to the Commissioners to: please can you fund that is treatment, because if they don't have it, they're going to die anyway.

So this was prior to NICE approval.

Going back -- I'm sorry, I've missed a bit because the important bit was that Professor Thursz said in his email -- and it is documented, it's in my evidence -- that there were all sorts of obstacles being put in the way by NHS England, as to why they shouldn't fund the treatment. And Professor Thursz

said they were inventing the obstacles, he said, as they went along then. And he blamed the Chief Pharmacist. I probably better -- can I say his name?
MS FRASER BUTLIN: Absolutely.
MS KELLY: Malcolm Qualie, so he was the pharmacist who was preventing that happening. Professor Thursz and the hepatologists took great exception to it, Matthew Cramp was involved, the hepatologist from Plymouth, and they were the experts, they were the specialists. They were the doctors. They were saying what needed to happen. And this was being contested by the NHS Commissioners and a pharmacist who knew nothing about hepatology, nothing about liver disease, and they would have the final say.

So the decision was basically just on funding. It was nothing to do with clinical need.
MS FRASER BUTLIN: Can I take you back to Wales --
MS KELLY: Yes.
MS FRASER BUTLIN: -- and what you did in relation to the Welsh Government.
MS KELLY: Yeah, so then we went to Welsh Government, obviously I brought this up at the All-Wales Advisory Group, and basically we were able to get an interim commissioning policy for the severely ill, and that was quite early. That was in the summer --

MS FRASER BUTLIN: 2 July 2014.
MS KELLY: Yeah. So I resigned from the Society and we just did it as our own group then, and we got an interim commissioning policy, and out of the -- there were six patients, but two of them went on to have liver transplants and they're still alive. So they had the treatment, and whereas we'd known so many in our group then that had died because they couldn't clear the treatment, and once they had a transplant, the tumours came back with greater force than ever before. This was a chance of life for these people.
MS FRASER BUTLIN: I should say we've had a response from Malcolm Qualie, which will be published on our website in due course, he rejects the contention that NHS England were inventing the process of making direct acting anti-virals available to patients and rejecting the contention that NHS England was creating hurdles to their access.

I just want to pick up one other matter which, Lynne, you've been very involved in, and Simon, in relation to achieving a coordinated approach to access -- to medical records. Lynne --
MS KELLY: Sorry, can I just say one -- I'm sorry to interrupt, but we then did get -- even though we that the interim commissioning policy, we then had it

rolled out for the whole of Wales. So everybody, within that year, regardless of how advanced their liver disease was, through the blood-borne viral action plan, everybody was treated and that was in conjunction with the hepatologists in Wales. And, basically, they treated everybody and there was no waiting list. So we didn't have any of the problems that they had in England with accessing treatments or having to show that they had cirrhosis before they were given the treatment. Sorry.
MS FRASER BUTLIN: In relation to access to medical records for the purposes of the Inquiry, you worked to achieve a coordinated approach to that, didn't you?
MS KELLY: Yes.
MS FRASER BUTLIN: The end result was a single email address that patients could email for their medical records.
MS KELLY: Yeah.
MS FRASER BUTLIN: Then it's right, isn't it, that you wrote to all the chief executive officers of the Welsh Health Boards --
MS KELLY: Yes.
MS FRASER BUTLIN: -- asking for a concerted approach to --
MS KELLY: Yes, and they all agreed to do that and they

were really helpful. And, you know, the records office in the -- in Cardiff they had one person who coordinated everything. So if people needed their medical notes, they could email this one person, and she would make it her job then to make sure that all those notes were put together to save, you know, distress to patients then, and their families.

MS FRASER BUTLIN: Simon, you've worked similarly with the Belfast Trust meeting them on a number of occasions, to agree an approach to accessing medical records.

MR HAMILTON: Yes, that's correct. This really stemmed from a problem with my brother Nigel when he sought records initially, he had difficulty accessing them and, in fairness, the Trust came back. We talked to our legal team, Watkins & Gunn, who were extremely helpful with this process and they accompanied us to several meetings with the Trust. Those were positive meetings. In fairness, we felt that the Trust was very willing to cooperate and help and I think the background to that is because of the changes in the management of records over a long period of time, we're talking about 30, maybe 40 years, it was an "industrial task", to quote the Trust, finding that information, and accessing it.

I have to say, we had number of meetings, and

those meetings potentially could have been ongoing, but without the very useful method in the sense that we had a contact from the legal team who worked with a contact from the Trust, and that's expedited the process of accessing materials, and we were very impressed that some of Nigel's records, which initially couldn't be found, dating back to handwritten records in a particular kind of log book, they were found somewhere in the archives of one of the buildings where all the records were being kept, and I think that facilitated the expeditious identification of records across the Belfast Trust and further afield for other sufferers within Northern Ireland.

Yes, so that was a good experience and a positive one. And I think an observation I would have made from some of the public local meetings which were held during the Public Inquiry, that individuals who hadn't -- who had worked on their own who had gone independent, as it were, struggled to find records or to access them as easily.

MS FRASER BUTLIN: The final substantive topic before we deal with just a couple of matters, and it's relatively brief.

Bill, you've said in your statement that funding

for Haemophilia Scotland remains a formidable challenge. What can you tell us about that in terms of the position?

MR WRIGHT: Well, I take my hat off to my colleagues here. Simon has no support in terms of employees and nor does Lynne, so I stand in awe. Because we're fortunate to have two members of staff. I'm afraid it I was a bit grumpy in my written statement in terms of the demands that this Inquiry has made on us because, obviously, it's taken a lot of effort, and we're now in a position in Scotland where, in order to secure the continuing employment of our chief executive and our engagement officer, we basically have to do it on a funded basis.

I have long experience of this. Advocacy is a desperately difficult thing to get funded. Support, family events, Lynne's run family events, as has Simon in Northern Ireland. But in the initial years, when we became established, we were in the fortunate position to employ Dan Farthing. He previously worked with The Haemophilia Society and had huge experience of the issues involved, and has given a written statement.

And for the first three years we got £100,000 a year from Government. That then came down to 60,000

and to 50,000, and in recent times it has been 25,000. Now, you can't pay two salaries on £25,000. So yes, please, I remember badgering Lynne and indeed Simon about -- in awe of this, you guys need to get some money out of this, because you can't go on like this.

MS FRASER BUTLIN: Lynne, what's your experience?

MS KELLY: Well, our concern as a group, as I say we're all volunteers. We didn't want it to curtail our campaigning, because we thought if we were having funding from Welsh Government, we might be restricted on how much we could campaign for a Public Inquiry, whereas we were sort of able to say what we wanted at meetings, and we could challenge them. So I understand the difficulties, and I suppose -- I'm the chair, you know, and I run it from home but are trustees will all have other jobs as well, and this is a full-time job for me, but it's worth it to get justice for everybody.

So it's not top of our priority list at the moment, because we want to make -- we want the Inquiry to report.

MS FRASER BUTLIN: Simon, any views?

MR HAMILTON: Well, we're a small organisation. We're all volunteers as well. So that resonates very much with me what Lynne was saying, and I do appreciate Bill's

help and guidance when we were starting up. It's been very useful to be able to pick up the phone and get ideas from others with more experience.

It's just around funding, the reality of funding is it would enable us to provide better services, better advocacy and more help to those that we are trying to serve. And I think that is the reality. We will always be a small organisation with a very small turnover but all of that money goes back into events and guidance, and we have good relationships with the clinic, and we can draw on experts from there and be given a little guidance. We have regular meetings with the consultant Dr Benson on an annual basis to discuss issues and needs, and to share ideas, and to give our feedback to him.

But we are really -- we would appreciate a little more understanding from the Department and I'm fairly confident with my own general experience of life that we would not be incumbent on the Department if we were given some support. It was difficult enough to actually find access to a room. This meeting today is taking place from my place of work in the boardroom, and that's where we've held our meetings, by and large, because it was virtually impossible to access anywhere else.

In all of those numerous buildings that are empty and vacant in the evenings, within the three hospital services which are within the vicinity of Belfast, we found it difficult to -- to believe that we couldn't access anywhere. But we're happy to go it alone. We're happy to do it our way, if that's the way it has to be done, and we will continue to do that.

But, there's no doubt about it, additional funding would make a big difference to the kind of service and the kind of information and the benefits to the people we are trying to serve.

MR WRIGHT: Could I just pick up Lynne's point because I think it's a very important point here, about who pays, because this is an issue that's arisen in relation to pharmaceutical funding, as well. I think we've possibly all had -- for specific events, had far more money for specific events.

MS KELLY: We've had it -- if we done -- like, we do children's events, so we'd ask for funding for a one-off weekend because, obviously, as a charity we rely on donations, and for us to raise £10,000 to take all the children in Wales on a weekend, that's a lot of money for us, so we usually -- we ask pharma. We don't always get it but we ask for it, but it has no

influence over what we're doing. And we support the families but I think we run it very much as a basic charity. We do a lot of advocacy work for people of all ages with haemophilia.

We've also, strangely enough, we've also made friends with lots of transfusion families and victims as well. But as regards -- the Public Inquiry has to be the most urgent thing now for us, rather than funding.

MR WRIGHT: The point being, in relation to what Lynne is saying, our integrity is such, as trustees of a charity, that we would not be influenced by that pharmaceutical firm if we were to run an event such as Lynne is talking about. And it's very specific to that particular event.

The other matter, and unfortunately, Dan has a sore experience of this, the regulations around pharmaceutical funding are tightening, are becoming tighter and tighter.

MS FRASER BUTLIN: Final two questions. When you reflect on your campaign work, the three of you, and that of those you know in the community, why, in your view, have efforts in the campaign been resisted in the ways we have spoken of over the time?

MS KELLY: I think there's a deliberate attempt to cover

up what happened. The government doesn't want to get to the truth. And so, whichever way you attack it, there are just obstacles in the way and the progress is blocked, there are falsehoods about the events that happened, and that just gets repeated and repeated and repeated by successive governments because, as I think was Bill said earlier, the civil servants don't change. Those civil servants are in post for a number of years. And the civil servants, you know, they have that mantra. They invent that mantra. We saw it with the self-sufficiency, the Department of Health report on self-sufficiency.

So basically we had the Archer Inquiry, 2007. In 2006 the Department of Health, they published a report. It's not named. It's just the Department of Health and blood products and self-sufficiency in the UK from 1971 to -- or 1973 to 1991. And in that are basically all the falsehoods that the Government has supported over the years. And that's repeated in the House of Lords and it's repeated in correspondence to victims. When people write to their MPs, you get a standard letter from the Department of Health saying that there was no fault, everything was done, this report has been issued and basically, you know, it was an accident. And it's not an accident.

MS FRASER BUTLIN: Bill, Simon?
MR HAMILTON: Yeah, if I could, I think inevitably Government, and the structures in the Government, ie, the Civil Service, have forgotten their calling. And their calling is to serve honourably and honestly. And I think they have neglected that charge.

I think as a consequence they have forgotten that we depend on them, and therefore their chief responsibility is to look after us properly. And when that doesn't happen, and it cannot -- it may not happen for a number of reasons, it is their responsibility then paternally and maternally to accept that they must do things to make that different.

The key fact, really, is, it is not the responsibility of Government -- and it shouldn't be, of a moral Government -- to defend the past when the past is wrong. Their responsibility is to address the future and provide a resolution and a solution in the future.

The only people who are capable of doing that are Government ministers in the highest parts of office. They are responsible, they take the knock. They are responsible for making the decisions. And they should take those decisions and accept that it is

perfectly all right to say something was done incorrectly and wrongly in the past and to address it about for the future. That is doing their job as we expect them to do it. And that's all that I could say on the matter.
MS FRASER BUTLIN: Bill?
MR WRIGHT: Yes. Government. Ha!

If ever there was evidence of Government, of us scaring them, having harmed us, having not looked after people and allowed people to die through NHS treatment, it's the issue of Crown immunity.

Now, my understanding is that some bright spark somewhere in Government sought to exert this on us. We're not soldiers. We're people that were harmed. So my understanding is that, legally, it could never actually have been applied to us. But what worries me here is that they were scared of us. They'd done something to us. That they didn't like. Somebody, some bright spark somewhere came up with this idea, so: "Let's dampen this down, let's defend ourselves against these people". Like Susan Deacon did in the early days of the Scottish Parliament. "Let's fight them in the courts. Let's do everything we can to stop this."

So I welcome the tenacity of this Inquiry. And

I really hope that we get to the bottom of -- get into places we've never been able to get at in this story. We've at least had the advantage in Scotland of the 15-year rule. What about the 30-year rule? What about the 50-year rule that might be exerted upon all of this?

So yes, I agree. I think Government doesn't -- we had a duty of candour in Scotland that was introduced after -- the idea started to flourish after 2007. We gave evidence because we had felt the whole cover-up thing needs to stop. Let's open things up. Unfortunately that doesn't apply strategically, it only applies in cases in clinical circumstances.

Sorry, I've just got cramp.
SIR BRIAN LANGSTAFF: If you want to stand up, that's fine.
MR WRIGHT: Sorry, sir. Oh dear.
MS KELLY: Bill, I would say that from my experience, and I think yours is the same, it's the civil servants. The governments change but the civil servants remain. And, you know, it's rotten. With regard to -- it's rotten to the core.
MR WRIGHT: I'd say, sir, that -- you know, Lynne, the number of times you must have travelled backwards and forwards between Cardiff and London, and Simon and

I haven't done that, we live in the outer Celtic reaches rather than the closer Celtic reaches. But for me, these people are a waste of time, you know.

I think we do want -- Government is going to have to take some action as a result of this Inquiry, and the Inquiry -- the words "we're investigating a cover-up", thank you, I think that is what needs to happen. The only problem is it's 10, 20, 30 years too late.
MS KELLY: And I think also for us, you know, it's very difficult to get meetings with ministers. It's only that, you know, I was fortunate, through Della, who lost her son, and Lynne, who is Baroness, that we were able to get access to those meetings, and she was able to then ask questions in the House of Lords about -- you know, like, the 10-year rule as the reason for the destruction of Lord Owen's papers, and Lynne was able to get it confirmed that -- by Lord Prior of Brampton -- that there is no 10-year rule. So, you know, they're just lies.

The Department of Health self-sufficiency report, that's now been withdrawn. And that's down to Lynne opening the doors for her and I to go to the meetings. It just wouldn't have happened. And to challenge those key officials in the blood policy

unit, like Rowena Jecock, who, over the years, must have seen all of the people in Wales, all the campaigners in Wales that have died, and made false promises to them. And ignored them. You know, it's just -- it's disgusting.

And yet they're in positions of authority, and they block. They block and they block and they block because it's all about money and just covering it all up.

MR WRIGHT: Counsel, can I make one further observation about this point?

It's not just a failure in Government, and governance. The Parliamentary process, if you look at what's happened in Westminster, we've had umpteen Health Committee examinations of this matter in Scotland. Has the Westminster Parliament Health Committee ever seriously looked at this matter in all the decades it's happened?

MS FRASER BUTLIN: Sir, those are the questions I have for the panel. I'm conscious that we need some time for the recognised legal representatives to indicate if they have any further questions. I wonder if we might take a short break for me to be able to do that.

SIR BRIAN LANGSTAFF: Well, yes. How long do you think we might need?

MS FRASER BUTLIN: Twenty minutes.

SIR BRIAN LANGSTAFF: Shall we then say quarter past five, no earlier than.

MS FRASER BUTLIN: Thank you, sir.

SIR BRIAN LANGSTAFF: But be ready for quarter past five, if you please.

(4.54 pm)

(A short break)

(5.15 pm)

MS FRASER BUTLIN: Thank you, sir.

I've got three -- or we just need to make sure -- there he is. Simon has joined us as well.

I've got three questions from recognised legal representatives and then six matters raised by your own representatives.

If we start with those raised by the recognised legal representatives of other Core Participants. In relation to HIV-infected partners, so non-haemophiliacs, and the access to care and treatment that they have, what support and advocacy is provided and what's needed for HIV-infected partners of haemophiliacs in your view?

MS KELLY: Well, I -- we would be lobbying for equal access for partners as well, because, depending on where they choose to go for their HIV treatment, you

know, that should be done without question. They shouldn't have to wait on waiting lists and -- you know, they need to have priority access as well.

Obviously the numbers are very small, but that definitely needs to be -- that needs to happen. And they shouldn't be treated as, you know, secondary infected. They are primary infected. And they've suffered equally.

MS FRASER BUTLIN: Bill, Simon, do you want to add anything to that?

MR HAMILTON: I agree with Lynne. I think there are issues that need to be addressed to ensure that they are given a very fair and supportive and compassionate treatment, and that they are not left feeling isolated in any way. Or secondary, or less important in any way.

I know from a number of experiences that all sufferers have had within the bleeding community, in terms of even dental care going back to the old days, we were treated quite harshly and we were treated with deep suspicion. I think those days have gone. I trust they have for good. I know practice is much better. But I think it is really important, remembering how I felt at times, when I was being faced with treatment and by people who didn't

understand my circumstances, I think it's really important that we ensure that they are properly facilitated and supported and that they are clear that they get that treatment and support in the same compassionate way.

MS KELLY: And also, can I just add something? I think the point that Simon raises about dentistry and HIV, particularly with the HIV drugs and the impact on -- you know, on their teeth, they definitely need to have priority. Because, aside from the stigma and the difficulty finding a dentist, you know, this is an impact of a treatment that they've been given and they need to have partners as well -- as well as -- you know, as well as the infected.

MR WRIGHT: Could I ask you to repeat the question, please?

MS FRASER BUTLIN: Of course. What support and advocacy is provided and what's needed for HIV-infected partners of haemophiliacs?

MR WRIGHT: Ah. Um, well, I am familiar with cases in England. I'm not aware of particular cases in Scotland, but in relation to the "should" word, I completely agree.

MS FRASER BUTLIN: Linked to that, in relation to potentially infected families, in your campaigning

work, have any of you been aware of any discussion about a look-back extending to potentially infected family members?

MS KELLY: No.

MR WRIGHT: No.

MR HAMILTON: No --

MS KELLY: Which is -- sorry -- which is ridiculous, because obviously at the time, when people didn't know they were infected, obviously the family members could have been infected. We know obviously some partners were tested, but that does need to happen, definitely.

MR HAMILTON: Yeah, when we've been talking in previous times about these sorts of situations and scenarios, people have reflected on that and asked the question, but I can't say for sure that that has actually been practised.

MR WRIGHT: Are you just considering HIV here?

MS FRASER BUTLIN: No, I think the question relates to both HIV and hepatitis C.

MR WRIGHT: Well, through personal experience, after I was diagnosed, we had two children and my wife was never tested. And it got to the stage that, when our daughter became a teenager, we were in a perilous position. The problem is insurance, because it would have wiped us out, financially, if Rosie had lost her

job or her income. So it's a very dangerous place to be. And I think, like other parents, I would have found it impossible to live with myself if my son and daughter had been infected.

MS FRASER BUTLIN: Bill, another question I've been asked to ask. You referred to the financial review and the presentation from Jan Barlow. What was it about the presentation that convinced you that you wanted nothing to do with the Alliance House organisations?

MR WRIGHT: Um ... she wasn't the only presentation we had. We had lots of different presentations, but I don't know if it just simply lacked enthusiasm. We'd had bad experiences. Our membership, during the process, had had bad experiences, and I just don't think she was able to answer the questions in response to the feedback that we'd had from members of both the Scottish Infected Blood Forum and of Haemophilia Scotland.

MS KELLY: And I would add that I've had correspondence many times with Jan Barlow and it's never amounted to anything at all and, every time I've contacted her, she would ask for confirmation of who I was, even though I would copy the person that had asked me to resolve a problem into the email to her, and there'd be maybe two or three emails just confirming who

I was, because she didn't who I was every time I wrote to her.

MS FRASER BUTLIN: It was quite specific about the financial review, thank you, Bill.

MS KELLY: Sorry.

MS FRASER BUTLIN: Lynne, I've been asked to ask about two matters, one is, I think, more of a point of information arising from your statement than a particular question, you note in your statement that your grandfather was a haemophiliac who lived until he was 76 and your great-uncle, also a haemophiliac, lived until he was 92.

MS KELLY: Yes.

MS FRASER BUTLIN: Is that right?

MS KELLY: So my grandfather he worked underground, and in later life he worked on the railways, and he had seven children. And his brother -- also, his brother -- actually, he worked -- he was a civil servant and he became the Mayor of Pontypridd, and he lived until he was, I think he was 91 or 92, but yeah, whatever I've said in my statement, yes. So it demonstrates that, you know, the fact that it said to us -- I've gone to lots of meetings in the Department of Health and they've said "Oh, all the haemophiliacs would have died at 23", I think is the number they quote. Well,

that's just not true, because our family are living proof and I know other families in Wales where the grandfather, you know, lived, with interventions, but a relatively normal life. And, you know, they had children and yet it was the next generation then, the generation, like my generation, my cousins.

MS FRASER BUTLIN: In terms of support you've received, Lynne, I understand you've had quite a lot of support from the Irish Haemophilia Society. Again, is that right?

MS KELLY: Yeah. So it was in 2015 -- well, when I was a trustee, I first met Brian O'Mahony, who's the -- at the time I think he was -- I think he was the chief executive at the time of the Irish Haemophilia Society. And he was also involved in the World Federation and the European Haemophilia Consortium. And as a trustee, I went to two conferences; and Brian basically, you know, presented on advocacy in action. And that's where -- I looked at their society and I could see that they'd got the settlement in Ireland, you know, and it seemed to be the best one that was on offer.

And basically, he highlighted all the areas of advocacy. He went through his campaign and how they got it, and, you know, I replicated a lot of that in

our campaign. But basically Brian is himself a haemophiliac and also with family members as well.

I would say that when Lord Morris was alive, Lord Morris would go and ask Brian O'Mahony's advice about things, and there will be examples of that in Hansard where he's asked Brian O'Mahony to -- you know, for advice or to ask for further information about the Irish scheme. And I just feel that the Irish Haemophilia Society in Southern Ireland, you know, it's an exemplar charity, and it's a really good example of how a charity can work. It doesn't need to be infected blood in one area and younger families in the other area. I think it needs to -- it's a generational thing. And I just feel that Brian should be asked to give evidence to the Inquiry, because he really does set a very good example of a successful society.

MR WRIGHT: Could I just support what Lynne is saying in terms of the Irish Haemophilia Society being an exemplar. We look at it enviously, because -- the qualification that I'll put on that in relation to funding is it received, since the Lindsay Inquiry huge Government funding.

MS FRASER BUTLIN: Bill, I've been asked to look at a document, WITN2287021, a meeting from

25 November 1999, a meeting with senior representatives of the Scottish National Blood Transfusion Service in Edinburgh.

MR WRIGHT: Yeah.

MS FRASER BUTLIN: I think you did attend. I think your name has been redacted out of an abundance of caution or an error on our part, but you were at that meeting, weren't you, Bill?

MR WRIGHT: I certainly was.

MS FRASER BUTLIN: What was the purpose of the meeting?

MR WRIGHT: It followed -- I'm just looking at the timing of this, actually. We were already making -- this was in the very early days of the Scottish Parliament. We were making representations to ministers by then. And I think one thing that Susan Deacon did do, and I suspect it was probably her that arranged this, in that she, I suspect, instructed these very senior people from the Scottish National Blood Transfusion Service to meet with many of us, and for them to explain what had happened from their particular perspective, but also for us to be able to ask questions.

MS FRASER BUTLIN: What did you learn about the possibility of ALT testing as a surrogate test for hepatitis C?

MR WRIGHT: Well, if I can just take a moment to remind -- go into my mental filing cabinet here.

The context for this was that, at the time, I'd been working in the world of the environment where we talked about indicators, and the precautionary principle. And by then, I had really hooked onto the whole thing about ALT testing, and the reason for that was the confidence that the days after I was infected -- the total confidence in 1986 that my raised ALT levels were confirmation of my own infection, and that led me to be thinking about, well, hang on a minute here, they were able to confirm for me. So the donors, one of those donors in those thousands of blood donations that led to my infection, one donor somewhere must also have had raised ALT levels and had been infected.

And that raised for me the whole issue about screening, and that then, during the questioning, during this session, it came out from Brian McClelland -- and I remember this quite vividly, he talked about raised ALT levels and his words were, "Well, we wouldn't have been able to eliminate someone because of possible false-positives, because", his words were, "they'd had a good drink in them the night before". In other words, alcohol raised ALT levels.

Subsequently, of course, we were able to find out that gamma GT is an indication of raised -- of alcohol. But what also came out of that was that the main consideration appeared to have been, within the Scottish National Blood Transfusion Service, was volume, in terms of blood donations. They didn't want to scare the donors, and that became very evident during this particular meeting.

MS FRASER BUTLIN: What impression did you have of the way in which the SNBTS conducted the meeting?

MR WRIGHT: [Laughs]

Um ... I think, yeah, a bit defensive. A bit patronising. Particularly the chairman, Angus Macmillan Douglas, who we later came across again when we appeared in front of the Health Committee.

MS FRASER BUTLIN: We spoke about the petition that was proposed, and we spoke about it as being one of the Scottish Infected Blood Forum. It was in fact proposed by the Scottish Haemophilia Groups Forum.

MR WRIGHT: That's correct.

MS FRASER BUTLIN: Can you tell us briefly about what the difference between the two groups is?

MR WRIGHT: The Scottish Infected Blood Forum was formed much later. The Scottish Haemophilia Groups Forum was, in effect, an amalgamation of the local groups of

The Haemophilia Society in Scotland.

I moved back to Scotland in 1996, and I was buttonholed and introduced to members of the Tayside group by a couple who lived close by in Perth and unfortunately neither are -- they're no longer with us.

And it was very much led by the late Philip Dolan, and he was tenacious. He could be a very difficult man at times, Philip, but he was tenacious.

And so the difference is it kind of petered out. It was a Scottish committee that was -- London felt they needed, to reinvigorate matters of the Scottish Office, and appointed.

Latterly Philip identified that there was -- people who had had blood transfusions were really not provided for in Scotland and it was a separate charity. But we worked very, very closely with them. And I must emphasise the importance of that particular charity that -- who are our close partners. We have joint meetings with -- every, I don't know, three months or whatever.

And they did two things in particular that were really useful. Robert, on Tuesday, referred to a bit of artistic work that he did -- well, the SIBF

sponsored a similar exercise but they also then -- I think they were funded by Scottish Government to conduct a scoping exercise, which in many ways was -- it came out around the same time as the Penrose Report. The bit of artistic work that was done -- and I'm sorry, I'm a bit tired and can't remember the complete detail -- it was important because it gave the opportunity to people who wanted to appear and tell their stories in a way that Lord Penrose hadn't allowed.

MS FRASER BUTLIN: Before we come back to the Penrose, which -- I have another question to raise with you. Just to be clear, the Scottish Infected Blood Forum is for those who either have been infected because of a bleeding disorder or because of a transfusion. It's both groups.

MR WRIGHT: Yes, we have a crossover, and there's members in both. I mean, we have people who have come to us in Haemophilia Scotland who had transfusions.

MS FRASER BUTLIN: In relation to the Penrose, how many campaigners were asked to give oral evidence?

MR WRIGHT: None.

MS FRASER BUTLIN: And what was the impact on the infected and affected community of that decision?

MR WRIGHT: Well, in line with the terms of reference, it

frankly meant that we didn't ... we didn't get to throw some of the accusations at Government that I've just thrown today, frankly, and bring it -- or, another way of putting it might be, to bring evidence to that particular inquiry.

Philip in particular was deeply frustrated. He spent 20 years of his life and he was turned down. I was put forward, and equally was turned down.

MS FRASER BUTLIN: Finally, when we -- we've heard talk a lot about Nothing About Us Without Us.

MR WRIGHT: Yes.

MS FRASER BUTLIN: In that context, what access -- and it's really a question for all three of you -- what access do you think that patients should have to medical information about them?

MR HAMILTON: I think it's fundamentally important to understand. I mean, what we're talking about is a trust relationship, what we're looking at now is a breakdown of trust. And, therefore, there needs to be a balance in how that information is shared. But it needs to be shared.

It comes as a rather a surprise to find that one might have spent ten years being observed with a potential illness that one wasn't being informed about and then afterwards being assured, in my case,

that I definitely had stage 2 hepatitis -- cirrhosis of the liver. So those things come as a surprise.

I think building relationships on trust is fundamentally important and that breakdown in trust is something which I think has to be restored, and has to be restored in such a way that it won't be broken again.

Perhaps regulation is a way of ensuring that happens, by standardising practice, professional practice, but I think there needs to be an understanding and an acceptance that there's a certain risk in that process and there needs to be some protection around that risk for those who share that information.

MS FRASER BUTLIN: Lynne, Bill, do you want to add anything?

MS KELLY: Yeah, I think obviously, you know, it should be transparent and I think it shouldn't just be something that Government says is going to happen. I think it should actually happen. It's one thing when ministers say, in the Lords, you know -- I think one of the phrases is, you know -- I think again it was Earl Howe said this "The absence of patients in the development of services is often a -- or is always a reason for their failure", and that would be in Hansard. And

yet, at the same time, they're restricting services and they're -- it's not being based on clinical need. It's being based on how much the Government can afford.

MR WRIGHT: Sorry, I'm going to ask you to repeat the question.

MS FRASER BUTLIN: Absolutely. In relation to -- we've heard lots about Nothing About Us Without Us. In relation to the provision of medical information, what access do you think patients should have to medical information about them?

MR WRIGHT: Well, I'm going to chuck something out there. I believe there's a strong case, and we've discussed this within Haemophilia Scotland, for a duty that each time there's a medical document of any significance produced, a legal duty to provide a copy of that to the patient.

I'll draw an analogy here. The two most private things our life are our health circumstances and our financial circumstances. Can you imagine going to a bank and them saying "You're fine", they don't tell you what your bank balance is, they don't tell you what the ins and outs are in your account. That's the situation that we face to this day. And I've had -- I say this from experience as a patient, which is

a very mixed experience.

I remember one time I had an endoscopy. At the end of the endoscopy, the nurse took me through, sat me down, gave me a sandwich and said, "Right, I want you to sit here and listen to me and here's two pieces of paper I want to take way of with you to explain what's just happened and what the results are".

To this day -- I mean, I recently had a bit of a scare, a bit of a chest scare. I had a chest X-ray and blood samples and I had to ring my own surgery to get the results. So I'm throwing out that -- that out there. I understand there will be a great wailing and gnashing of teeth because I've actually spoken to an administrator within the haemophilia world in Scotland, quite a senior individual, and the reaction was "Wow, there's clearly a cost to that". But can you just imagine a bank manager saying -- can you imagine if you went for private healthcare -- we pay taxes -- can you imagine them saying, "Well, no, we're not giving you any paperwork to follow it up."

And if you look at this disaster and medical records going missing, then that has been one of the key issues in all of this, throughout the evidence that the Inquiry has received.

The second point I want to make about this is

the question of the duty of candour. Yes, the Scottish Government has done good stuff on that. In 2018 we gave evidence to some of the MSPs on the Health Committee about it because we felt it was important, it's part of the lessons being learned, but it's not at a strategic level, and this goes back to the question of cover-up.

MS FRASER BUTLIN: I'm just going to look behind me.

Sir, do you have any matters to raise?

Questions from SIR BRIAN LANGSTAFF

SIR BRIAN LANGSTAFF: Yes. The first couple of questions for you, if I may, Bill. Let me just press you a little bit further on the question that was asked about why Jan Barlow's presentation was so unpersuasive. The reasons you've given are that, in effect, it was lacklustre and that she couldn't answer questions that were then asked. Now, that's very much a reflection of one person, their reaction. What you were considering, I take it, was the future structure of the health -- the arrangements for paying money to those who had been infected and affected.

What was it about the AHOs that led you to think that they were not the right vehicle to do that?

MR WRIGHT: Well, the question of accountability, sir. You've received evidence on the AH from some of the

trustees of the AHOs. I have some experience of charity governance, and much larger charities than ours, with tens of thousands of acres of land, 40, 50 employees, and the question of -- the impression I've received from that evidence, which is consistent with the impression we received at the time with Jan Barlow, was that, in effect, they were like NDPBs, but the Government was able to say that's their decision.

I remember in particular there was one bit of evidence about them not going out to fundraise. Charities have to go out and fundraise. But they were reliant -- their only source of funding was the Government. So, in effect, they were NDPBs but it was convenient for Government.

Now, one of the questions we were asked during the financial review was "Which model do you want to arrive at?" and the Minister was open minded about that. But we reached the conclusion that accountability was important. And the Minister supported us in that. In fact, she left a legacy, and there are some views in Scotland that maybe it needs to be a bit arm's length, but the legacy was, as I said earlier, we can go back and pin these guys down about the way that those -- that the Scottish scheme

is being operated.
SIR BRIAN LANGSTAFF: Thank you.
The second question is also about the review of financial arrangements in 2016, when you told us that Scottish Government came to you and said, "Well, we'll go with a median wage."
MR WRIGHT: Yes.
SIR BRIAN LANGSTAFF: 27,000. Was there any discussion in that meeting that you can recall about the question of whether any account should be taken of the spouses or the partners or the carers who may have sacrificed their own earnings in order to care for the person who was the primary, in this sense, beneficiary?
MR WRIGHT: I'm grateful you raised that, sir, because the legal definition under the Act in two thousand and ... oh, sorry, wrong Act. The legal definition that -- after the Ross Report and the Skipton Fund was formed, used the term "definition", where we started discussions with Scottish Government about that very matter.
This is 2021. My wife is not my dependant. My god, if I was to suggest that ...
And similarly with partners.
With sons and daughters who were children, it has proven advantageous on occasions in order for

financial support to be continued for them. But that is a matter that needs to be examined pretty closely.
SIR BRIAN LANGSTAFF: The point I was perhaps asking about was, suppose that a partner has lost part of the job that he or she may have done, they may be working part-time, ten hours a week, instead of full-time, 38 hours a week. They may have had various other expenses which come with that.
The person who has been infected has no income, because they can't work -- at least, little income, because of their infection. They may be attributed 27,000, and that may add 15, 20,000 to what they already earn. But the partner has already lost, and part of the overall cost to that household is the loss of his or her income.
MR WRIGHT: At that point during your deliberations, that particular point you're talking about in terms of carer, rather than being dependent, being a carer, which is what I think, sir, you're getting at --
SIR BRIAN LANGSTAFF: It is. It's the costs of caring.
MR WRIGHT: Yes. In other words, if you draw an analogy with litigation in terms of settling litigation care costs, no, that -- that was something probably missed -- and similarly with adult children who'd

never been compensated. And worst of all, with parents who'd lost children.
So that we didn't -- and that's one of my biggest regrets, but balancing the time imperative that we -- we'd press Government on at that point. And certainly I feel -- and I'm sure colleagues would agree -- that's something that needs close examination now.
SIR BRIAN LANGSTAFF: The next is really to you, Simon. It's -- you were explaining that the ideal, in terms of future funding arrangements in respect of any form of support, whether ex gratia or whether compensation or for those who have suffered, should be paid for out of the HM Government funds, central funds, and I understood you to be saying essentially there ought to be central funding but local management. Have I got it right?
MR WRIGHT: [Laughs] -- (overspeaking) --
MR HAMILTON: -- (overspeaking) --
SIR BRIAN LANGSTAFF: This is for Simon, so let him go first, then you have your chance for the constitution.
MR HAMILTON: I think, first of all, I would like to be clear that I believe that central Government has the responsibility because, going back pre-devolution, this is a problem prior to devolution, and therefore

it's about the responsibility and accountability of that.
The other issue is that effectively, there are -- it depends on the nature of devolved Government and the relationship with the United Kingdom Government, in terms of how monies are separated, divided, awarded, provided, in general practice.
I know the reality of the situation in Northern Ireland is that if Northern Ireland were to be given the responsibility and our Minister of Health has said he would be listening, and responding positively to the -- if I understand him correctly, responding positively to any recommendations coming out of the Inquiry, the reality is that no matter how well intentioned he is, he would not be able to provide the recommendation to its -- to any level, because the recommendation I would anticipate, if there were one, would be so significant and substantial, or substantive, that the current budget would be inadequate to meet it, and therefore it could not be achieved.
And under those circumstances, I think the responsibility has to fall with central Government and the Treasury.
How it is finally arranged is not as big an

issue for me, to be honest with you, and I think for other -- for other victims and other recipients, that wouldn't be as significant an issue, but I can understand -- and I can almost hear Bill saying that, for him, it would be. And I understand, because of the differences in Government, from where we are at the moment, our Government would be looking to central Government to provide them with something which then they would be passing on.

SIR BRIAN LANGSTAFF: So, for Simon, it doesn't particularly matter where those sums are administered. Bill, and then Lynne, what about Scotland and Wales? What's your view?

MR WRIGHT: Well, Bruce yesterday raised a question of what's this money for, in terms of the treatment of people with haemophilia. And he, you know, he made some pretty strong assertions that obviously the Inquiry will look at.

I think this is -- we've given this a lot of thought, because we get into a whole constitutional wrangle about a post-devolution Government and a pre-devolution -- when the disaster really all commenced -- we're still living the disaster, but the disaster commenced prior to devolution. I've consulted with legal colleagues about this, and it

goes back to what was the will of Parliament at the time that devolution took place, in terms of -- in terms of -- and I know the Inquiries Act doesn't allow us to look at liability but, in many senses, Scottish Government has inherited the liabilities of the Scottish Office.

But until this Inquiry examines those issues of -- and says -- I'm sorry, sir, I'm putting this back in your plate, to actually look at what went on within Government, I don't think we can answer that question.

SIR BRIAN LANGSTAFF: So you ask for simple funding but leave it up to me to decide who administers it.

MR WRIGHT: [Laughs]

SIR BRIAN LANGSTAFF: Simon says he doesn't mind. Lynne, do you have a position?

MS KELLY: Well, I believe the funding needs to come from central Government. Obviously we -- in Wales, we've worked hard to get this holistic approach but, that said, there are people in our group who don't use that anyway. So I think it'll be a question that we put out to our members in our next discussions about how they would feel, you know, if it was centrally funded.

I think the features of our scheme, I think, you know, are good, and they work, but then there are

people in the group that say, "Well, I don't need that support, I don't need the welfare advice. I don't need all of that, I would prefer it -- I would prefer to have financial recompense for that rather than the scheme, the all singing and dancing scheme". But I think that would be -- I couldn't answer that until we've spoken to everybody about that.

SIR BRIAN LANGSTAFF: So you're arguing for a local solution, even if it is to accept central management?

MS KELLY: Not really. You know, I think we have to have -- we have to have this -- the facility where there's face-to-face contact and, you know, financial support -- sorry, psychological support. But I think it just has to be all funded centrally. So -- because obviously in Wales, we have the scheme, and we have the -- it's based in South Wales but for the people in North Wales, that's four or five hours away. So it does have a -- you know, a problem of logistics.

So in South Wales it's all close by, but for the people in North Wales, that's not the case.

MR WRIGHT: Sir, having had the impertinence to bat this back to you, could I ask that there is a further consideration here. The schemes tend to operate on a payment monthly, and that is important. And that was something we considered during the financial

review.

One thing we never did during the financial review in Scotland was present the opportunity to then convert that off into a one-off payment, such as happens in Ireland.

There's a middle house here, because one-off payments, in terms of compensation, there was additional money paid at that time and, therefore, I had a discussion at senior level about this in terms of whether it's easier for Government to pay a great big -- a whole lot of money at once or to spread it out over the years. So there is a consideration here about, not only enhancement of the schemes on a monthly basis or yearly basis but also in terms of a capital payment.

MR HAMILTON: Sir Brian, forgive me, may I make one other point?

I think in the context of the experience we've had in Northern Ireland, with a great sense of insecurity around the continuation of Government, without punctuated breaks that last up to three years, if a recommendation came forward, and it was -- it was the responsibility of devolved Government to deal with that and Government wasn't functioning, effectively, the experience of the last three years indicates that

we would be waiting, and that is something which would be totally against the spirit and the principle of a conclusive arrangement. So that influences me in a way that my colleagues wouldn't be influenced, I think.

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

MS FRASER BUTLIN: I think each of you wanted to say something to close.

Simon, would you like to start?

Statement by SIMON HAMILTON

MR HAMILTON: Yes, thank you very much. I just prepared something because I had several thoughts on this, but I will be very brief. And it answers your question originally, sir, in relation to my early negative conclusion, and thank you for giving me the chance to say something.

I was critical of the progress of Government in the conclusion of my campaign statement. I highlighted the obfuscations, strategies of delay, verbal assurances, endless meetings and correspondences which encouraged me to wait patiently while the big cogs of Government and the bureaucracies of Government ground slowly. But time doesn't wait while the process animates itself. Throughout this

period of frustration and stress, people were and are despairing and dying, lives were and are deteriorating.

Uncovering the facts about personal harm and injury is a painstaking process. This process is greatly magnified when it is a question of how Government deals with the health and wellbeing of those of us who innocently and haplessly trusted the State to care for us. Both medical and Government bureaucratic decisions have turned the infected and affected blood community into victims.

We trusted our health practitioners and we ended up as victims. We trusted Government on two previous inquiries, and we ended up as victims. This cannot happen again. I've spent the last six years of campaigning metaphorically screaming out that delays are not the way to resolve the wrongs of the past. In fact, the chorus from many campaigners is the same: there's only one practical way to clean up the human trail of emotional and physical debris that lies at the Government's feet; that is to acknowledge its existence, and to acknowledge that it needs to be put right.

As I said to the Right Honourable David Lidington in 2019, there's no moral

justification for defending the past, when you can correct the future.

As I now review the situation after much campaigning and much disappointment, I actually have some hope. I've seen that light has been shone and process has responded, and issues long fought for have been hard won, but won nevertheless. Parity, whatever that means, is being achieved. And there is an acknowledgement that there is a moral obligation on Government to clean up the human debris trail by redeeming itself from the horror of the past and the pain of the present. What is only left is the future.

Victims in Northern Ireland have tasted the sweetness of acknowledgement and compassion.

Only because we have a Health Minister in Robin Swann who accepted that he should address what others have failed to do, and in so doing, he has proven that when Government accepts its moral responsibility, it fulfils its duty to its citizens.

What we need is what we have always needed: central Government acknowledging its responsibility and acting swiftly, as you once, Sir Brian, requested.

So I will continue as one with the endurance and determination to run for miles if I need to, because I stand ... I stand in a line with all other victims,

whether looking ahead or looking back, looking to the left or looking to the right. We cannot give up on ourselves.

Thank you.

[Applause]

MS FRASER BUTLIN: Lynne?

Statement by LYNNE KELLY

MS KELLY: I feel privileged to be here today, giving evidence to the Inquiry on behalf of Haemophilia Wales and the people we represent. The campaign to bring this disaster into the public domain has succeeded because of the continued efforts of victims and campaigners against the orchestrated and deliberate attempts by successive governments and others to conceal the truth.

This campaign has truly been fought on the shoulders of giants. They fought the lack of transparency, accountability and willingness to engage for over 30 years, and we will not forget them, or their perseverance.

We have heard in this Inquiry from those in positions of responsibility at the time who cannot remember, did not keep records or trouble themselves to understand or accurately recall the details that led to the deaths of over 3,000 people in the UK.

The lack of transparency, accountability and willingness to come to terms with the past to prevent this happening again continues.

There remains an unwillingness of some to properly engage with key individuals and campaigners still excluded from decision-making forums. There still exists a lack of transparency of funding sources, to quote the Welsh Health Minister's evidence, where, like the medical records, "money appears from the back of the sofa."

And there is still the lack of accountability, where families -- sorry, there is still a lack of accountability, where people responsible retire to enjoy the benefits denied to the infected and their families.

Victims and families will never forget what happened or the response of those who should have had their interests at the centre of their duties. If they ever thought Government was their friend, they now understand it is not.

We hope the Inquiry will finally get to the truth about what happened and ensure that victims and families receive the compensation and support needed to allow them to live what is left of their lives in the dignity they're entitled to.

Thank you.

[Applause]

MS FRASER BUTLIN: Bill?

Statement by WILLIAM WRIGHT

MR WRIGHT: I've got a great big long list of wants, duty and -- documents have talked about duty of candour.

Pharmaceutical hazard fund, in other words we stop nationalising the losses while pharmaceuticals make vast profits in the cases where people have been the subject of trials.

There's an ongoing situation in Scotland with regard to Patient Safety Commissioner, and I remain, and I really do hope, that the Inquiry can look at what happened in public health terms here because, to me, there was a public health disaster and the public health officials were nowhere to be seen throughout this process. So they were the missing bit of the jigsaw that previous inquiries simply haven't looked at.

However, I'd like to bring this much closer to home for me. When we met on Saturday, I was chairing the meeting of -- joint meeting of the Scottish Infected Blood Forum and Haemophilia Scotland and said, "Folks, how are you all feeling about this?" and the message came over "We're exhausted, we're weary

but, my God, we're resolute".

After that, a widow phoned me and talked to me privately. I continue to do that and I'm sure Lynne has a similar experience, and Simon as well. She was really struggling because what was important to her was the need to be believed.

She felt that all her power had been removed and, because of that removal of power and not being believed, she felt the need to be able to trust -- the thing she really wanted was to be able to trust again, and this is important because this disaster, because of the financial implications, and the health impacts, has removed choices.

She revealed her sense of vulnerability to me. And we've talked about Nothing About Us Without Us, and I hope that we may look at this process in the future. But I go back to how I got involved in all of this, and Robert, on Tuesday, talked about some names, some first names.

For me the equivalent names are John and Pat, Philip, brothers Dave and Ian, and also another John. But then, there were the men, and they are largely men -- there are some women but there were the men who were the husbands and the fathers that I never met. Dave, Davy, Peter, Tom, Billy, I'm sorry to the widows

whose names I've not included because the list goes on and on.

And, finally, the wee boys. We need to have a memorial. Bruce talked about it yesterday, I agree and Robert illustrated what can be done, thanks to the Birchgrove Group.

We need to mark this in time and, yes, we must provide for people, but we must never ever forget, and one of the main ambitions I have in Scotland -- we have in Scotland, and these people who do these things that raise money for this memorial keep us going and they're a tremendous inspiration.

So it's for those people that I think we need to continue to act and to continue to be resolute. Thank you.

[Applause]

SIR BRIAN LANGSTAFF: You may have wondered, perhaps others may have wondered, why today we have chosen to have the three of you as a panel. I think those who are listening will be left in no doubt that in your very different ways, you have expressed much of the same feelings, given much of the same evidence, though with regional variations, as appropriate to devolution.

I suspect that in this way, by having the three

of you together, you have allowed the voices that you have said need to be heard to be expressed, if not directly to the Inquiry, through you, because each of you represents a body, and it is important to hear the representatives, the heads of those bodies, talking to us on their behalf, as well as on your own individual side.

The impact of what has happened, on you and on others, but essentially what you've been giving evidence directed to, within our terms of reference, is the impact on you, on those you represent, on others that you know of, and the appropriateness of the Government response. And it's varied and the expression of it is varied. I think few of us will ever forget your emphatic oratory, Bill, and the way in which you've left us in no doubt as to your strong feelings on matters of principle, and your championing of the individual at the heart of it all, whoever that individual may be.

Simon, you've expressed yourself in, well, rather different terms, but very eloquently. You described yourself, for instance, in terms that Bill wouldn't I think have used today, as "less than enamoured", on one occasion, by a Government response. I think he might have put it rather differently.

And you, Lynne, have always been mindful of the fact that you speak for a community, and you need to be sure that the community are properly reflected in what you say because they are a wide and diverse group.

But I've heard from each of you, I think, and I think you've expressed your own campaigning -- if I can call it that, to use a word Bill doesn't like -- in terms of that you've shown us that you -- it's rather quieter perhaps, the evidence you've given, than Bill, but there is -- I've seen a steely determination running through your persistence in asking questions and waiting for the answers.

But each of you, I think, has drawn attention to the need for compassion, openness, the need to avoid delay. On that, by the way, if I can just say, I'm sorry that because of the need to avoid delay which you've each touched on repeatedly, that there may have been pressures put upon you by the Inquiry to respond. It's inevitable and is one of the reasons I thank you for being prepared to give up your time, not simply in being here today, which goodness knows that's enough of an effort, particularly from Scotland these days, and not being as well as you might be, but also preparation beforehand, which takes a lot of effort.

And it has been, I hope, as worthwhile for you as it has for us.

But also, I think you've expressed a collective sense of having been wronged, and a collective desire for accountability. And for a continuing voice. I'd like to thank you for that, for being here to do it for being prepared to put up with the difficulties of having a panel, having to be quiet at times when you might have wanted to speak, and being conscious of the fact that you have taken different approaches reflecting your different areas but giving each of them value in the very different ways.

It's been a new experience for us to do it this way, but I think it's been worth it. Thank you.

[Applause]

Tomorrow?

MS FRASER BUTLIN: Tomorrow we have Jason Evans giving evidence.

SIR BRIAN LANGSTAFF: Ten o'clock. So ten o'clock tomorrow.

(6.13 pm)

(Adjourned until 10.00 am the following day)

I N D E X

F:

F:

F:

F:

F:

F:

F:

F:

F:

F:

F: