1	Monday, 26 September 2022	1	W4211 and any other identifying information, such as
2	(10.00 am)	2	the witness's image or a description of their
3	(Proceedings delayed)	3	appearance, cannot be disclosed or published in any
4	(10.30 am)	4	form unless express permission is given by me or by
5	SIR BRIAN LANGSTAFF: Welcome to the six of you and the	5	the solicitor to the Inquiry acting on my behalf.
6	seventh who is anonymous. Let me deal with the	6	Witness W4211 must be referred to only as Mr BD.
7	position of that anonymous witness first, if you don't	7	That's bravo delta BD. This order remains in force
8	mind.	8	for the duration of the Inquiry and at all times
9	My apologies though to you and to those who are	9	thereafter unless otherwise ordered, and I may vary or
10	listening for the delay there has been this morning.	10	revoke the order at any time by making a further order
11	It has been for logistical reasons. I don't think	11	during the course of this Inquiry. As always, it is
12	it may be a reflection of the fact that we have quite	12	vital that you respect and everyone listening online
13	a number of you together, which will make for a very	13	respects the anonymity of our anonymous witness.
14	interesting day talking about the Skipton Fund and	14	Mary, would you administer please the oaths to
15	refusals and lack of records in particular, but	15	those who are on the panel. Can we start with Andrew
16	telling your stories as well.	16	Bragg, please.
17	But first let me speak about that witness, the	17	MR ANDREW JAMES BRAGG (sworn)
18	witness who is anonymous. You will not see that	18	SIR BRIAN LANGSTAFF: Gary McKelvey.
19	witness on screen, I will. For that reason, although	19	MR GARY HUGH MCKELVEY (affirmed)
20	Mary will administer the oaths and affirmations in the	20	SIR BRIAN LANGSTAFF: Ruby Gilkes.
21	usual way to those witnesses that we have on the panel	21	MS RUBY PERLINE GILKES (affirmed)
22	before you, I will be swearing in the witness who is	22	SIR BRIAN LANGSTAFF: Peter Frith.
23	in this building but is not seen.	23	MR PETER FRITH (affirmed)
24	I have granted that witness anonymity and so	24	SIR BRIAN LANGSTAFF: Rachael Tersteeg.
25	I make this order: the name and address of witness	25	Ū.
	1		2
1	MS RACHAEL JOY TERSTEEG (sworn)	1	mind being a little closer to the microphone. That's
2	SIR BRIAN LANGSTAFF: Robert Bamforth.	2	perfect, thank you.
3	MR ROBERT NORMAN BAMFORTH (sworn)	3	You had a broken ankle but it was quite a severe
4		0	
5		4	break?
	SIR BRIAN LANGSTAFF: Now, Ms Fraser Butlin, we are not	4	break?
	going to hear I think from our anonymous witness this	5	MR ROBERT BAMFORTH: Oh, yeah, everything was broke right
6	going to hear I think from our anonymous witness this morning and so that witness will take the oath, or the	5 6	MR ROBERT BAMFORTH: Oh, yeah, everything was broke right across. It was hanging one a different way. Then
6 7	going to hear I think from our anonymous witness this morning and so that witness will take the oath, or the affirmation I should say, at the start of this	5 6 7	MR ROBERT BAMFORTH: Oh, yeah, everything was broke right across. It was hanging one a different way. Then I shouldn't have been skateboarding at 40, really,
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(1) Pages 1 - 4

4	MC EDACED DUTUN. After the exercition to belt back the	4	MC EDACED DUTUN. 100/2
1 2	MS FRASER BUTLIN: After the operation to bolt back the ankle, what were you told about giving blood in the	1 2	MS FRASER BUTLIN: HCV? MR ROBERT BAMFORTH: HCV, that's it. But it said I could
2	future?	2	only get it through sharing needles as a drug addict
4	MR ROBERT BAMFORTH: Well, they said when you have had	4	or sex. So you can imagine what my wife of seven
5	an operation you shouldn't give blood for they	5	years thought when she heard that. You know what
6	didn't say forever, they just said you shouldn't give	6	I mean.
7	blood for a while, you know, a year or something like	7	MS FRASER BUTLIN: After you received that letter what
, 8	that.	, 8	happened with your marriage?
9	MS FRASER BUTLIN: At the time of the operation, were you	9	MR ROBERT BAMFORTH: It just finished. It broke up.
10	told anything about having blood transfusions? Sorry,	10	MS FRASER BUTLIN: And how quickly did that
11	you will need to	11	MR ROBERT BAMFORTH: Oh, within weeks. You know,
12	MR ROBERT BAMFORTH: No. Sorry. No.	12	because I don't know, she thought I'd either been
13	MS FRASER BUTLIN: Thank you. About two years after the	13	playing around or she just didn't want to know how
14	operation you decided to give blood again?	14	I had got the infection. You know?
15	MR ROBERT BAMFORTH: Yes.	15	MS FRASER BUTLIN: You then went to live with your mum at
16	MS FRASER BUTLIN: And you did so again in 1993 as well	16	that point?
17	is that right?	17	MR ROBERT BAMFORTH: Yes.
18	MR ROBERT BAMFORTH: Yes.	18	MS FRASER BUTLIN: You also went to see your GP?
19	MS FRASER BUTLIN: Can you tell us what happened after you	19	MR ROBERT BAMFORTH: Yes.
20	gave blood in 1993?	20	MS FRASER BUTLIN: What did your GP tell you about
21	MR ROBERT BAMFORTH: Well, I got a letter from the blood	21	hepatitis C?
22	transfusion people telling me I've got, what's it, HC	22	MR ROBERT BAMFORTH: Oh, that's the luckiest thing I had
23	something or other	23	because he had just read up on because they had
24	MS FRASER BUTLIN: Hepatitis C?	24	only just found out about hepatitis C, they didn't
25	MR ROBERT BAMFORTH: No, they didn't say	25	know what it was, and he found out that King's College
	5		6
1	Hospital were doing a pilot scheme, doing tests on it	1	it neither you know
1 2	Hospital were doing a pilot scheme, doing tests on it, and he sent me straight there rather than to the local	1 2	it neither, you know. MS FRASER BUTLIN: I think at that appointment he asked if
2	and he sent me straight there rather than to the local	2	MS FRASER BUTLIN: I think at that appointment he asked if
2 3	and he sent me straight there rather than to the local hospital, which wouldn't have known anything about it.	2 3	MS FRASER BUTLIN: I think at that appointment he asked if you had had any significant operations?
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(2) Pages 5 - 8

1	which was quite devastating because you lose faith in	1	treatment in 2008 and that did clear the virus?
2	what's happening then, don't you, you know what	2	MR ROBERT BAMFORTH: Yes, but I had that for 18 months.
3	I mean? Because I was quite happy having the	3	MS FRASER BUTLIN: Were you very unwell for those
4	treatment, because anyone who has had the treatment	4	18 months?
5	realises it is horrendous and, you know, then you	5	MR ROBERT BAMFORTH: Yes.
6	think, well, I'm going to have to have this again	6	MS FRASER BUTLIN: In terms of your working life, once you
7	or well, I didn't know if they would give it to me	7	were diagnosed with hepatitis C, at that point you
8	again or whatever, you know. I asked them what would	8	were working as an aircraft engineer?
9	happen, you know.	9	MR ROBERT BAMFORTH: Yes.
10	MS FRASER BUTLIN: What can you tell us about how the	10	MS FRASER BUTLIN: What happened in relation to your
11	first treatment round was, what was it like for you?	11	working life once you were diagnosed?
12	MR ROBERT BAMFORTH : The funniest thing was the first day,	12	MR ROBERT BAMFORTH: I had to give that up. You know, two
13	I went and had the injection, and I got home and they	13	things: one, it was physical and I couldn't really do
14	told me not to be on my own that night, but I my	14	it; and, two, working with metal, you cut yourself and
15	son was with me and I said to him, "Go home, I feel	15	that, and I was terrified that because I might work
16	all right". I said, "I don't feel that good but	16	on a bit and someone else has to work on it and I was
17	l feel all right", then about half an hour, an hour	17	terrified that I was going to give it to someone else,
18	after he went I couldn't control my body. I started	18	you know.
19	going into a ball, my muscles it was really odd and	19	Lucky, when I left school I learnt to be a barber
20	my arms are coming up, my legs are coming up, and it	20	and I have got managed to get a job in a barber
21	was really odd. But I never had that after that, you	21	shop, so at least I kept working, but it cost me
22	know. The next all the other times it was all	22	the first treatment cost me I had a house but I had
23	right. But you are just so tired and you just it	23	to get rid of that because I was starting to get in
24	is a nightmare really.	24	financial trouble. And I sold the house and bought
25	MS FRASER BUTLIN: You then had a second course of	25	a flat because I had to keep a roof over my head, you
	9		10
1	know what I mean I actually didn't put that in my	1	MC EDACED PUTLIN: How did you come to hear about the
1	know what I mean. I actually didn't put that in my	1	MS FRASER BUTLIN: How did you come to hear about the
2	statement but it you know, I thought if I'm not	2	Skipton Fund?
2 3	statement but it you know, I thought if I'm not going to be able to work because I didn't know if	2 3	Skipton Fund? MR ROBERT BAMFORTH: My son had a friend who his wife
2 3 4	statement but it you know, I thought if I'm not going to be able to work because I didn't know if I was going to be able to work or not I thought if	2 3 4	Skipton Fund? MR ROBERT BAMFORTH: My son had a friend who his wife had got infected and she had been gone through the
2 3 4 5	statement but it you know, I thought if I'm not going to be able to work because I didn't know if I was going to be able to work or not I thought if I didn't work how do I pay my bills? I couldn't pay	2 3 4 5	Skipton Fund? MR ROBERT BAMFORTH: My son had a friend who his wife had got infected and she had been gone through the Skipton Fund and got paid out and I never met her but
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2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	 statement but it you know, I thought if I'm not going to be able to work because I didn't know if I was going to be able to work or not I thought if I didn't work how do I pay my bills? I couldn't pay a mortgage, so I bought a one bedroom flat that I didn't have a mortgage on, you know. MS FRASER BUTLIN: So you were diagnosed and moved from being an aircraft engineer with a regular salary to being a barber? MR ROBERT BAMFORTH: Yes. MS FRASER BUTLIN: Where you were, effectively, self-employed? MR ROBERT BAMFORTH: Yes. MS FRASER BUTLIN: Then you had the treatment? MR ROBERT BAMFORTH: Yes. MS FRASER BUTLIN: And you were worried you wouldn't meet the bills? MR ROBERT BAMFORTH: Well, yes, because I couldn't work every day. I would get up some days, especially when you had to inject, the days you had to inject you have to eat before you do it all. I lived on my own, so you try and cook a meal, get something to eat, then it takes you hours sometimes to get down to eating, you 	2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	 Skipton Fund? MR ROBERT BAMFORTH: My son had a friend who his wife had got infected and she had been gone through the Skipton Fund and got paid out and I never met her but my son found out about it so I just got in touch with them and got the forms through and just sent them off. MS FRASER BUTLIN: So before you decided to contact Skipton and make that contact because of the friend of your son, had anybody mentioned the Skipton Fund to you before that? MR ROBERT BAMFORTH: Not at all, no. MS FRASER BUTLIN: So you applied in 2009? MR ROBERT BAMFORTH: Yes. MS FRASER BUTLIN: For your application did you have any medical records in relation to your operation? MR ROBERT BAMFORTH: I tried to get medical records and then Lister said they didn't have any records. MS FRASER BUTLIN: So the hospital said they had no records? MR ROBERT BAMFORTH: Yes. Funny enough, the second time they'd got them because they'd got no record of me having any blood, they said they've got no record of me having any blood.

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MR ROBERT BAMFORTH: Yes, sorry. 1 transfusion. 1 2 MS FRASER BUTLIN: It's okay. You applied for your 2 MS FRASER BUTLIN: Your application was then refused and 3 3 records first time and what were you told that time you sent further documents to the fund including 4 from the Lister? 4 letters from doctors since your diagnosis setting out 5 MR ROBERT BAMFORTH: Just didn't have them. 5 their view that it had been a transfusion acquired 6 MS FRASER BUTLIN: No records. Then you tried to get the 6 infection; is that right? 7 records a second time, and what were you told then? 7 MR ROBERT BAMFORTH: Yes. They reckoned because I didn't 8 8 have it before I had the broken leg and then I had it MR ROBERT BAMFORTH: Well, they come up with some records, 9 but it was only about my broken leg, nothing about --9 straight afterwards, they said it must have been that 10 10 well, I did think I'd sent you a copy. and -- but the Skipton just said no. MS FRASER BUTLIN: Can you recall what those records MS FRASER BUTLIN: So you supplied those letters to 11 11 contained when you did get a few records from them? 12 12 Skipton. Then I just want to look at the refusal from 13 MR ROBERT BAMFORTH: Well, it just said about how 13 Skipton, if we can put that on the screen. 14 they'd -- it's words I don't even understand, you know 14 WITN4414013, please. 15 what I mean. These doctors use words, you know what 15 It is just the middle two paragraphs, and reading 16 I mean? As far as I was concerned it was a broken 16 out so everyone can follow: 17 ankle, but it was H, B, C and D, and all that. It 17 "It is with regret that I must advise you your 18 didn't mean a lot to me what it said. 18 application has been declined. This is due to the 19 MS FRASER BUTLIN: You also obtained your GP records is 19 lack of supporting confirmation that you were treated 20 that right? 20 with NHS blood or blood products prior to 21 21 MR ROBERT BAMFORTH: Yes. September 1991 and that this was therefore the likely 22 MS FRASER BUTLIN: But there was nothing at all in those 22 source of your infection with hepatitis C. 23 records about blood transfusion? 23 "On two of the letters we have received (one from 24 MR ROBERT BAMFORTH: No, I don't think they had anything 24 2000 and one from 2001) it mentions a past transfusion 25 25 there about the broken leg, let alone a blood but in the absence of medical records this was 13 14 1 presumably as a result of consultation between you and 1 up. Everything I have had in life I have had to work 2 2 your doctor. Of course, if you do obtain any other for so I don't expect to get anything from anyone, you 3 3 supporting medical records then please return these know 4 along with your application form and we will consider 4 MS FRASER BUTLIN: And the Inquiry has seen the forms that 5 5 it again." are required for an appeal and so they are familiar 6 So those letters they are referring to were 6 with the detail that is hard to provide. 7 7 letters from your treating doctors in the 2000s? Thank you. 8 MR ROBERT BAMFORTH: Yes. 8 MR ROBERT BAMFORTH: That's all right. 9 MS FRASER BUTLIN: Who had said to you the likely cause of 9 SIR BRIAN LANGSTAFF: May I just ask this, looking at the 10 your infection was a transfusion? 10 dates of the information which recorded that the 11 MR ROBERT BAMFORTH: Yes, or blood product. 11 probable cause was a blood transfusion, both of those 12 MS FRASER BUTLIN: That second sentence that says, of 12 dates are before the Skipton Fund began. 13 course, if you do obtain any other supporting medical 13 MS FRASER BUTLIN: Yes. 14 records, were there any other supporting medical 14 SIR BRIAN LANGSTAFF: And indeed before it had been 15 records that you could have got hold of? 15 announced. So there could have been no prospect of 16 MR ROBERT BAMFORTH: No, because the hospital said they 16 that being said for gain at all. 17 MS FRASER BUTLIN: Indeed. didn't have any at that time. 17 18 MS FRASER BUTLIN: Did you appeal this decision? 18 SIR BRIAN LANGSTAFF: Thank you. 19 MR ROBERT BAMFORTH: No. MS FRASER BUTLIN: Thank you, Robert. 19 MS FRASER BUTLIN: Am I right that's because you have 20 20 Rachael, you are here to talk about your late 21 quite severe dyslexia? 21 husband Cornelius, who was always referred to as Con 22 MR ROBERT BAMFORTH: Yes. 22 by you and the family. 23 MS FRASER BUTLIN: So for you that just wasn't an option? MS RACHAEL TERSTEEG: That's right, yes. 23 MS FRASER BUTLIN: So we will also refer to him as Con, as 24 MR ROBERT BAMFORTH: You know, just -- you look at forms 24 25 and it just -- it's a nightmare. So I just give it 25 you wish. 15 16

(4) Pages 13 - 16

1	MS RACHAEL TERSTEEG: Thank you.	1	MS RACHAEL TERSTEEG: The doctor first of all had said
2	MS FRASER BUTLIN: Con was admitted to hospital on	2	that he they wanted the abscess to get a little bit
3	10 April 1987, is that right?	3	bigger so that when they would drain the abscess they
4	MS RACHAEL TERSTEEG: That is correct.	4	would be able to hopefully aspirate as much of the pus
5	MS FRASER BUTLIN: Why was that?	5	as possible, and they were doing a CT scan to monitor
6	MS RACHAEL TERSTEEG: He had flu-like symptoms, he was	6	that progress.
7	feeling very unwell, he wasn't able to walk very well.	7	As we were waiting for that decision to be made,
8	It was as if he was having a stroke. Wycombe Hospital	8	which was then two days, he wasn't able to see out of
9	transferred him during the night because he	9	his left eye because the abscess was on the right side
10	deteriorated. He went to Oxford, Radcliffe Infirmary.	10	of his brain and the whole of his left side was
11	They did scans and, when I arrived the next morning,	11	paralysed. He couldn't speak properly, the side of
12	they said he had an abscess and that was growing	12	his mouth was turned up, so it was as if he had had
13	underneath the skull and on his brain, and they were	13	a stroke. Those were all of his symptoms.
14	going to monitor the abscess and then they were going	14	MS FRASER BUTLIN: Can I just turn to a document,
15	to operate when they felt that that was the right	15	WITN2720002.
16	time.	16	It is what looks to be the blood ordering form for
17	MS FRASER BUTLIN: And the cerebral abscesses had	17	13 April.
18	developed because he had contracted beta-haemolytic	18	The next page, please.
19	streptococcus, is that right?	19	It is not entirely straightforward to read but we
20	MS RACHAEL TERSTEEG: That's right.	20	can see the date of 13 April 1987 that blood had been
21	MS FRASER BUTLIN: A craniotomy was planned for 13 April	21	requested.
22	1987, but it didn't actually take place until	22	MS RACHAEL TERSTEEG: Yes.
23	15 April, is that right?	23	MS FRASER BUTLIN : On the left of the date there is a box
24	MS RACHAEL TERSTEEG: That's right, yes.	24	where a number 2 has been written, and below and to
25	MS FRASER BUTLIN : What was the reason for the delay?	25	the left we can see cells.
	17		18
1	Your understanding of this form is that some form	1	but they would have to wait and see how his recovery
1 2	Your understanding of this form is that some form of blood product or packed cells had been ordered for	1 2	but they would have to wait and see how his recovery would be because they didn't know what damage may have
	of blood product or packed cells had been ordered for	2	would be because they didn't know what damage may have
2	-		would be because they didn't know what damage may have been done with the paralysis and how his body would
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1	with a local anesthetic under the scanner to see how	1	
2	a patient would respond without having to go through a	2	
3	general anaesthetic. But he said it was the	3	
4	absolutely worst thing he had ever been through.	4	
5	The all the things you could see around you, the	5	
6	noise, the fact that, although you couldn't feel	6	
7	anything, it was a traumatic experience, in hindsight,	7	
8	yes.	8	
9	MS FRASER BUTLIN: Between 1987, when he had that surgery,	9	
10	and 2008, when we are going to come onto about	10	ľ
11	hepatitis C, can you tell us what Con was like and	11	ľ
12	what life was like together with him?	12	1
13	MS RACHAEL TERSTEEG: He was a lovely husband. He was	13	
14	really, yes, just so special. The first year was so	14	ľ
15	difficult because he was recovering from all the	15	
16	procedures, from the anesthetic, from the emotional	16	
17	trauma. He would try to walk himself a little bit	17	
18	further each day to try to help the mobility of his	18	
19	left leg, which he was able to walk, which was	19	
20	amazing. He did as much as he could do improve	20	
21	himself. And as the I mean, there was one time	21	
22	I remember, he was he got down on his knees on the	22	
23 24	floor, he was banging on the floor, like this, and he said, "Why me? Why did I have to go through this?"	23	
24 25	But that was just getting through that that first	24 25	
25	21	25	
	21		
4		4	
1	see Dr Gorard.	1	ľ
2 3	MS FRASER BUTLIN: We will come to that in just a moment, but if we go back to that letter with the blood test	2 3	ľ
4	form in, did you ever get to the bottom of why that	4	ľ
5	was sent to Con?	5	'
6	MS RACHAEL TERSTEEG: Not at all. The Dr Graham, he	6	ľ
7	didn't know why it had been sent from Oxford, no idea	7	
8	at all. There was nothing in his records of why it	, 8	
9	should be sent to us. We didn't have any idea.	9	ľ
10	MS FRASER BUTLIN: At that point was he still under any	10	1
11	follow up from the craniotomy?	11	
12	MS RACHAEL TERSTEEG: No.	12	
13	MS FRASER BUTLIN: He wasn't under followup from the	13	ſ
14	craniotomy and his GP hadn't requested that blood	14	
15	test?	15	
16	MS RACHAEL TERSTEEG: That is correct.	16	
17	MS FRASER BUTLIN: So as far as you're concerned, that	17	
18	request was a complete surprise?	18	
19	MS RACHAEL TERSTEEG: Absolutely, out of the blue.	19	
20	MS FRASER BUTLIN: You have put in your statement you	20	
21	think that was about March/April 2008?	21	
22	MS RACHAEL TERSTEEG: Yes.	22	
23	MS FRASER BUTLIN: As you said, you then had a private	23	
24		~ 4	
	referral to a liver specialist?	24	
25	referral to a liver specialist? MS RACHAEL TERSTEEG: Yes.	24 25	
25	•		

We had our two daughters who were young. Yeah, as he improved, we had a sort of small vegetable area garden, he would plant runner beans. We would go out sometimes as a family. We would just do things with the children. And those years weren't always easy but we got through them. He wasn't allowed to drive for the first year. I would take him to work every day and pick him up from work. MS FRASER BUTLIN: But he was working through that time? MS RACHAEL TERSTEEG: Through that year, yes. MS FRASER BUTLIN: How did Con come to know that he had hepatitis C? MS RACHAEL TERSTEEG: Out of the blue. We had a letter one day from Oxford Hospital with a form in it saying to just go and get a blood test done. So we duly went to Wycombe Hospital, the blood test was done, and we had a letter from the GP saying, "Please can you come in and see me". We went to see Dr Graham, and he said, "We need you to go and have another blood test because this is indicating that you may have hepatitis C". So we were really shocked about that. Con went and had another blood test done. Now that was confirmed. And at the time, because he had got private medical insurance, we privately went to go and 22 MS FRASER BUTLIN: And a liver biopsy was performed? MS RACHAEL TERSTEEG: Yes. MS FRASER BUTLIN: And what did that show? MS RACHAEL TERSTEEG: That Con was positive for hepatitis C, genotype 1 I think, yes. MS FRASER BUTLIN: That's what you've put here. Do you recall whether they said anything about how much damage to Con's liver there was at that point? MS RACHAEL TERSTEEG: No. MS FRASER BUTLIN: The biopsy was on 21 May 2008. Then Con started treatment with interferon and ribavirin in the August. MS RACHAEL TERSTEEG: Yes, that's right. Yes. MS FRASER BUTLIN: How did Con cope with that treatment? How --MS RACHAEL TERSTEEG: He had 48 treatments. He had to inject himself once a week, he had the interferon tablets daily to back that up, and it was an awful year. On a Friday evening, he'd -- he'd already planned and thought through that he would have the injection on the Friday evening because of the side effects of feeling poorly, flu, bad headaches, aches and pains, so that on a Monday morning he would have been through the worst to be able to go back in to work. And when he was having very bad days, again

year was really, really tough.

24

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1	I would take him into work and pick him up.	1	would have to go to bed, lie down and rest.
2	MS FRASER BUTLIN: Con cleared the hepatitis with that	2	MS FRASER BUTLIN: So you moved to a flat in 2011 to avoid
3	treatment.	3	that problem?
4	MS RACHAEL TERSTEEG: He did, yes.	4	MS RACHAEL TERSTEEG: Yes, we sold the house, it was
5	MS FRASER BUTLIN: But he was then very unwell after that?	5	a semi-detached house. We sold the house and moved to
6	MS RACHAEL TERSTEEG: Yes, that's correct.	6	a flat and so that there was it was just easy
7	MS FRASER BUTLIN: And he was diagnosed with oesophageal	7	access for him to get to the bathrooms.
8	stricture, leading to cancer of the larynx	8	MS FRASER BUTLIN: Then in 2013 you went to Holland for
9	MS RACHAEL TERSTEEG: That was just a year later, yes.	9	a funeral of a friend?
10	MS FRASER BUTLIN: In 2010. And then porphyria cutanea	10	MS RACHAEL TERSTEEG: Correct.
11	tarda, a skin condition with painful lesions on some	11	MS FRASER BUTLIN: And Con collapsed?
12	exposed skin.	12	MS RACHAEL TERSTEEG: Yes.
13	MS RACHAEL TERSTEEG: Yes.	13	MS FRASER BUTLIN: Again, can you tell us what happened
14	MS FRASER BUTLIN: In terms of your home, in 2011 you	14	then?
15	moved house.	15	MS RACHAEL TERSTEEG: Yes. He had flu-like symptoms on
16	MS RACHAEL TERSTEEG: That's right.	16	the Saturday evening, Easter Saturday. He felt
17	MS FRASER BUTLIN: Why was that?	17	really really quite poorly. He had a slight
18	MS RACHAEL TERSTEEG: We moved because Con's health had	18	temperature and by the evening he seemed completely
19	deteriorated. He was struggling getting up and down	19	disorientated. He didn't really he wasn't coherent
20	the stairs. We only had a bathroom upstairs and	20	in his speech. He was really poorly. And I phoned
21	l know that he would used to he would say, "Well,	21	the ambulance. They did all the obs, vital obs. His
22	I'll try and hang on as long as I can before I need to	22	blood pressure was really, really low. His heart rate
23	use the bathroom because then I don't have to go up	23	was racing. He was very poorly. They took him in to
24	the stairs". And in the afternoons he would oh,	24	the Apeldoorn Hospital. Within minutes there was
25	every weekend, you know, when he wasn't working, he	25	a whole team around him and anyway, he was taken up
20	25	20	26
1	to the ICI I word. He had get influenze A year hadly	1	MS DACHAEL TEDSTEEC: Voc
1	to the ICU ward. He had got influenza A, very badly,	1	MS RACHAEL TERSTEEG: Yes.
2	and he was just very poorly.	2	MS FRASER BUTLIN: Con also struggled significantly
2 3	and he was just very poorly. MS FRASER BUTLIN: He had major organ failure at that	2 3	MS FRASER BUTLIN: Con also struggled significantly mentally. Do you want to tell us something about that
2 3 4	and he was just very poorly. MS FRASER BUTLIN: He had major organ failure at that point?	2 3 4	MS FRASER BUTLIN: Con also struggled significantly mentally. Do you want to tell us something about that and how it was for you and the family?
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(7) Pages 25 - 28

1	and she recorded that because of what he had been	1	They said to us in the Skipton Fund that we would need
2	through, that it can affect your immune system. When	2	to have more evidence and suggested we write to Oxford
3	Con first had the treatment, we had to sign	3	Health Authority.
4	a disclaimer that he wouldn't father any children. We	4	MS FRASER BUTLIN: So once the first application had been
5	had to we were just aware that any colds that he	5	declined, Con then wrote back to the Skipton Fund.
6	got could easily become pneumonia, chest infections	6	l just want to look at that letter.
7	and throughout the period of from 2013 to 2016 we	7	COLL0000014, please, page 9.
8	always had antibiotics at home. He could	8	We see there, again I will just read it out:
9	self-medicate. He was often on there was periods	9	"I have only been able to obtain documents showing
10	when he had to take steroids to help him out of the	10	the blood products were delivered but unfortunately
11	infection and his immune system was just and	11	I have not been able to find any confirmation that
12	anything that was going he would pick it up.	12	they were administered during the procedure as the
13	MS FRASER BUTLIN: In 2016, before he was had the	13	'Recovery Area Record Sheet' was left completely blank
14	wound, Con had made an application to the Skipton	14	(copy's already forwarded)."
15	Fund?	15	We will come to the next bit in a moment. All
16	MS RACHAEL TERSTEEG: Yes.	16	that Con had been able to obtain was the document we
17	MS FRASER BUTLIN: When he made that application, what	17	looked at earlier and a blank recovery area form; is
18	medical records had Con been able to obtain?	18	that right?
19	MS RACHAEL TERSTEEG: At the point of first application we	19	MS RACHAEL TERSTEEG: Yes.
20	hadn't applied for any. He took a great interest in	20	MS FRASER BUTLIN: And there were no notes from the
21	news and he had read that the Skipton Fund had been	21	operation and for the full 12 hours later?
22	set up and that the government had now recognised	22	MS RACHAEL TERSTEEG: That is correct.
23	about the contamination, the Infected Blood Inquiry.	23	MS FRASER BUTLIN: The first record was just returned from
24	So he applied for an application form which was filled	24	ICU?
25	in by the GP and we sent that to the Skipton Fund.	25	MS RACHAEL TERSTEEG: Correct yes.
	29		30
1	MS FRASER BUTLIN: Just a complete blank. Then if we pick	1	MS FRASER BUTLIN: Apologies, indeed it was my
2	up the letter again:	2	typographical error in my notes, apologies. So 2014.
2 3	up the letter again: "Due to my hospitalisation I do not have enough	2 3	typographical error in my notes, apologies. So 2014. We see there that Con has offered a statement from
2 3 4	up the letter again: "Due to my hospitalisation I do not have enough time to get any more supporting information regarding	2 3 4	typographical error in my notes, apologies. So 2014. We see there that Con has offered a statement from you and if we could turn to that, it is page 10 of the
2 3 4 5	up the letter again: "Due to my hospitalisation I do not have enough time to get any more supporting information regarding the Craniotomy procedure but I want to put the	2 3 4 5	typographical error in my notes, apologies. So 2014. We see there that Con has offered a statement from you and if we could turn to that, it is page 10 of the same document please, Lawrence.
2 3 4 5 6	up the letter again: "Due to my hospitalisation I do not have enough time to get any more supporting information regarding the Craniotomy procedure but I want to put the following to the panel for consideration:	2 3 4 5 6	typographical error in my notes, apologies. So 2014. We see there that Con has offered a statement from you and if we could turn to that, it is page 10 of the same document please, Lawrence. We have a short statement which is signed by you,
2 3 4 5 6 7	up the letter again: "Due to my hospitalisation I do not have enough time to get any more supporting information regarding the Craniotomy procedure but I want to put the following to the panel for consideration: "1. My wife was informed by the doctor after the	2 3 4 5 6 7	typographical error in my notes, apologies. So 2014. We see there that Con has offered a statement from you and if we could turn to that, it is page 10 of the same document please, Lawrence. We have a short statement which is signed by you, we've just redacted the signature. You have set out
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(8) Pages 29 - 32

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1	expert members, was of the view, supported by the	1	MS RACHAEL TERSTEEG: Yes.
2	clinical records we have seen, that there is	2	MS FRASER BUTLIN: That's what we have on the screen. If
3	insufficient evidence to show that you were treated by	3	we it sets out what had happened. In fact, if we
4	a blood transfusion.	4	turn over the page, we have the paragraph dealing with
5	"The hospital records show that you underwent	5	your conversation with Dr Teddy:
6	a successful drainage of a brain abscess in 1987.	6	"Dr Teddy, the surgeon, was also present and he
7	This is a procedure for which a transfusion would only	7	told me that the surgery had gone well but they had
8	rarely be necessary. The hospital discharge record	8	given him a blood transfusion during the operation."
9	gives full details of the procedure and does not	9	If we go to the next page. You had taken this
10	mention any complication which might necessitate	10	statement and it was sworn in front of solicitors.
11	a transfusion. You had a good haemoglobin level of	11	MS RACHAEL TERSTEEG: Yes.
12	13.5 before surgery; that would make a transfusion	12	MS FRASER BUTLIN: So it was effectively a sworn witness
13	less likely to be needed.	13	statement?
14	"As a result of these considerations we were not	14	MS RACHAEL TERSTEEG: Yes, it was. Definitely.
15	satisfied that it is probable that the infection	15	MS FRASER BUTLIN: And this whole statement, with the note
16	resulted from qualifying NHS treatment and accordingly	16	that it had been sworn, was provided to the Skipton
17	regret that we must refuse your appeal."	17	Fund?
18	Con then challenged that response from the	18	MS RACHAEL TERSTEEG: Yes.
19	Skipton, particularly that it made no reference at all	19	MS FRASER BUTLIN: The appeal was then reconsidered but
20	to your witness statement, your note of what you had	20	still refused?
21	been told; is that right?	21	MS RACHAEL TERSTEEG: Yes, that's right.
22	MS RACHAEL TERSTEEG: That's right, yes.	22	MS FRASER BUTLIN: If we can go to a final document,
23	MS FRASER BUTLIN: If we go to page 25, Con responded	23	page 35 of this document. We pick up the second,
24	again, and this time you provided a very lengthy	24	third and fourth paragraphs:
25	witness statement of what had happened?	25	"The Chair has asked me to tell you that the Panel
20	33	20	34
	33		34
			with the Oligher Fred is relation to the mature of the
1	has reconsidered your appeal after one of the	1	with the Skipton Fund in relation to the nature of the
2	specialist medical members reviewed the whole file of	2	hepatitis C test, that it was out of the blue and
2 3	specialist medical members reviewed the whole file of your medical records. The conclusion is that on the	2 3	hepatitis C test, that it was out of the blue and unexpected?
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2 3 4 5	specialist medical members reviewed the whole file of your medical records. The conclusion is that on the existing records there is still no reason to conclude that it is probable that you were given a blood	2 3 4 5	hepatitis C test, that it was out of the blue and unexpected? MS RACHAEL TERSTEEG: That's right. Nothing at all. No. MS FRASER BUTLIN: How did that make you and Con feel
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(9) Pages 33 - 36

1	felt all the while just never being believed. And	1	you.
2	then when they said here where is it? Well,	2	Apol
3	they couldn't understand why the existing records	3	the whis
4	weren't there, as if we had taken them out ourselves	4	reached
5	or something. It was just awful.	5	Gary
6	MS FRASER BUTLIN: I think Con felt quite strongly that	6	father, H
7	they were minimising the surgery that he had	7	MR GARY M
8	undergone; is that right?	8	SIR BRIAN L
9	MS RACHAEL TERSTEEG: Yes.	9	bit close
10	MS FRASER BUTLIN: That they seem to be suggesting it was	10	talking a
11	a simple abscess drainage when, as you said, he had	11	help. If
12	a very significant scar?	12	MR GARY M
13	MS RACHAEL TERSTEEG: Yes. He did, yes.	13	Yes,
14	MS FRASER BUTLIN: Sir, I note the time that we would	14	to make
15	normally take our morning break, but, given that we	15	MS FRASER
16	started a little late, I wonder if I might take one	16	ulcer wh
17	more person through their	17	MR GARY MC
18	SIR BRIAN LANGSTAFF: Yes, that will be a good idea	18	maybe v
19	I think.	19	MS FRASER
20	MS FRASER BUTLIN: Thank you.	20	MR GARY M
21	Gary, you are here to speak about your late	21	and it m
22	father yes, I'm sorry, we still have a slight	22	mother y
23	problem with some documents so I'm going to move on to	23	to make
24	speak to Gary and then after the break we should all	24	MS FRASER
25	be sorted out and we will return to the other three of	25	stomach
	37		
1	of blood?	1	areas of
2	MR GARY MCKELVEY: Yes, I believe it was 18 pints.	2	there, so
3	MS FRASER BUTLIN: How did you and your mum know that he	3	MS FRASER
4	had been given that amount of blood?	4	wasn't q
5	MR GARY MCKELVEY: I have got to say I wasn't in the	5	MR GARY M
6	country at the time. I was in the United States. But	6	that time
7	she was told by the medical professionals at the time,	7	locked h
8	you know, with that type of surgery, the seriousness	8	over the
9	of that ulcer, that he had been given significant	9	that bruis
10	blood and it was 18 pints and she confirmed that again	10	have exp
11	yesterday. Because I said, "I have got 18 pints in my	11	his GP.
12	head", and she said, "Yes, that's correct, that's my	12	Agai
13	understanding".	13	time ago
14	MS FRASER BUTLIN: Your dad recovered fairly well?	14	platelet o
15	MR GARY MCKELVEY: He recovered totally, you know.	15	MS FRASER
16	MS FRASER BUTLIN: And what was his health like then until	16	transfusi
17	about 1990?	17	MR GARY M
18	MR GARY MCKELVEY: Health was fine, returned to work, no	18	l don't kr
19	issues, no other health problems, dental problems.	19	transfusi
20	Back to his usual self and, you know, what we've got	20	MS FRASER
21	to say is we were very grateful for the skills of the	21	Christma
22	surgeons who did the job in 1981.	22	MR GARY M
23	MS FRASER BUTLIN: And he was working in a shipping yard?	23	MS FRASER
24	MR GARY MCKELVEY: Yes, he was working in Harland & Wolff	24	and eme
25	and I noticed in the there is a montage of certain	25	MR GARY M
	39		

you.
Apologies, I should have said that. That was what
the whispering behind me was, they just haven't quite
reached everybody who needs them.
Gary, you are here to speak about your late
father, Henry.
MR GARY MCKELVEY: (Inaudible)
SIR BRIAN LANGSTAFF: You will have to bring that a little
bit closer to you. It is difficult because you are
talking across. So if you speak into it, that will
help. If you can.
MR GARY MCKELVEY: Thank you.
Yes, sorry, on behalf of my mother who is unable
to make the trip. So yes, my father.
MS FRASER BUTLIN: In 1980 your dad developed a stomach
ulcer which later ruptured?
MR GARY MCKELVEY: Yes, I would like to correct something
maybe within the statement.
MS FRASER BUTLIN: Of course.
MR GARY MCKELVEY: I read it in detail over the weekend
and it mentions 1980, 1981. I did speak with my
mother yesterday. She tells me it was 1981. So just
to make that clear.
MS FRASER BUTLIN: During treatment for that ruptured
stomach ulcor, your dad was given a significant amount
stomach ulcer, your dad was given a significant amount
38
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- as 1990?
- CKELVEY: Correct.
- BUTLIN: And your dad was taken into accident
 - ergency on New Year's eve?
- CKELVEY: Yes, I did take him myself, yes.

(10) Pages 37 - 40

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1	MS FRASER BUTLIN: What was wrong at that point?	1	stroke, so it was March 1991?
2	MR GARY MCKELVEY: Just his ankles, both, were very, very	2	MR GARY MCKELVEY: Yes, it was a couple of months after
3	swollen, excessively swollen, and he was just weak.	3	the stroke, yes.
4	I can't remember whether he struggled to work to be	4	MS FRASER BUTLIN: Your dad was extremely unwell from then
5	honest but I felt it was serious enough on New Year's	5	on?
6	eve to take him to A&E.	6	MR GARY MCKELVEY: Yes, he was.
7	MS FRASER BUTLIN: Your dad then had a stroke in	7	MS FRASER BUTLIN: What can you tell us about that?
8	January 1991?	8	MR GARY MCKELVEY: After the stroke he had come home but
9	MR GARY MCKELVEY: Correct, he did, yes.	9	frankly he just slept most of the time. He wasn't
10	MS FRASER BUTLIN: But how did your dad's hepatitis C come	10	able to do anything. I did come home on a few
11	to be diagnosed?	11	occasions because he didn't know how unwell he was,
12	MR GARY MCKELVEY: Honestly spoken, it was we were	12	and we didn't tell him how unwell he was. We knew, or
13	never told it was hepatitis C until my mother	13	we had been told that it was terminal, yeah, but we
14	recalls this as 17 March. Whether that is exactly	14	didn't tell him that. So let's say the level of his
15	correct, I don't know but that's what she remembers	15	unwellness was that, you know, I had to toilet him.
16	and the registrar or the junior registrar and, again,	16	And it is not a pleasant thing to do, you know, with
17	l don't know, a Dr Paul Kettle had been to	17	a 57 year old man, and, yes, he was only 57 at the
18	a conference apparently in London and, again, I don't	18	time.
19	know how accurate that is but he told her that having	19	At the time I probably thought that was quite old,
20	been and having listened he was of the opinion that my	20	you know, but on reflection I'm now four years older,
21	father had contracted hepatitis C through the blood	21	almost to the day, than he was when he died. So you
22	transfusions that he would have had in 1981.	22	have a different perspective as time goes on.
23	There was no explanation of what hepatitis C was.	23	MS FRASER BUTLIN: Your dad then was taken back into
24	That's the first time we had ever heard the term.	24	hospital
25	MS FRASER BUTLIN: And that was told to your mum after the	25	MR GARY MCKELVEY: He was.
	41		42
1	MS FRASER BUTLIN: And he died on 9 June 1991.	1	said, "Listen, remember what was spoken all those
1 2	MS FRASER BUTLIN: And he died on 9 June 1991. MR GARY MCKELVEY: Correct, yes.	1 2	said, "Listen, remember what was spoken all those years ago, that my dad received this blood which
2	MR GARY MCKELVEY: Correct, yes.	2	years ago, that my dad received this blood which
2 3	MR GARY MCKELVEY: Correct, yes. MS FRASER BUTLIN: Could we turn to your father's death	2 3	years ago, that my dad received this blood which Dr Kettle believed was infected from the surgery in
2 3 4	MR GARY MCKELVEY: Correct, yes. MS FRASER BUTLIN: Could we turn to your father's death certificate.	2 3 4	years ago, that my dad received this blood which Dr Kettle believed was infected from the surgery in 1981. Let's get some details on the Skipton Fund and
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1	MS FRASER BUTLIN: It is the Business Services	1	the Trust's policy."
2	Organisation who run the Northern Ireland Blood	2	They spelt retention wrong, but "retention and
3	Support Scheme, NIBS.	3	destruction of records". Yeah. I also wrote to the
4	In terms of the records your mum, I think, went to	4	Northern Health and Social Care Trust and had exactly
5	her own GP.	5	the same response.
6	MR GARY MCKELVEY: She did.	6	MS FRASER BUTLIN: So GPs couldn't help, hospital records
7	MS FRASER BUTLIN: What did her own GP said about	7	had been destroyed. At that point you then contacted
8	completing the form?	8	the Business Services Organisation on5 December 2017
9	MR GARY MCKELVEY: He said he could not complete the form	9	because it had shifted across?
10	because he was not my father's GP at the time and	10	MR GARY MCKELVEY: Yes.
11	there were no records so it was not practicable for	11	MS FRASER BUTLIN: What were you advised by them?
12	him to do that.	12	MR GARY MCKELVEY: I spoke with Mr Colin Murray at the BSO
13	MS FRASER BUTLIN: She had also written to the Belfast	13	and, you know, actually, he was very helpful on the
14	Hospital?	14	phone, which was the first time anyone had been
15	MR GARY MCKELVEY: She had.	15	helpful. But ultimately he was only able to come back
16	MS FRASER BUTLIN: What did they say?	16	with the same response: no medical records, there was
17	MR GARY MCKELVEY: No medical records existed.	17	no way forward, and that we should contact and my
18	MS FRASER BUTLIN: You then wrote to the Belfast Health	18	mother should contact her local Assembly Member,
19	and Social Trust?	19	called Stephen Farry, which is what she did, yeah
20	MR GARY MCKELVEY: I did, yes.	20	who in turn contacted Richard Pengelly, who was
21	MS FRASER BUTLIN: Again, what did they say?	21	l have forgotten his title.
22	MR GARY MCKELVEY: They said:	22	MS FRASER BUTLIN: He is the Permanent Secretary and HSE
23	"A further search was completed for any electronic	23	Chief Executive.
24	records, ie laboratory results, and nothing was found.	24	MR GARY MCKELVEY: Thank you very much, yes.
25	The requested notes have been destroyed in line with	25	MS FRASER BUTLIN: If we look at his letter in response,
	45		46
1	it is WITN0525002, please. It is the second and third	1	had already spoken to?
1 2	it is WITN0525002, please. It is the second and third paragraphs:	1 2	had already spoken to? MR GARY MCKELVEY: Yes, he was.
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traffic accident?

1 other panellists. 1 2 SIR BRIAN LANGSTAFF: Yes, it is. Let's take a break then 2 3 3 until 12.05 pm. I hope that gives you long enough. 4 MS FRASER BUTLIN: Sir (break in audio transmission) the 4 5 5 usual witness rule. 6 SIR BRIAN LANGSTAFF: No, I won't. 6 7 7 (11.36 am) 8 (A short break) 8 9 (12.05 pm) 9 10 SIR BRIAN LANGSTAFF: Yes. 10 MS FRASER BUTLIN: Andrew, if we can start this session 11 11 with your evidence. You are a chartered chemical 12 12 13 engineer? 13 14 MR ANDREW BRAGG: 1 am. 14 MS FRASER BUTLIN: And before you started work after 15 15 16 university in 1986 you went on a long holiday in 16 17 Norway? 17 18 MR ANDREW BRAGG: Yes, I graduated in 1986 as a chemical 18 19 19 engineer. I had had a chemical engineering 20 scholarship from ICI. That meant I worked through 20 21 21 university as well as studied, so I was looking 22 forward to having a break before I started work in 22 23 September. I have a lot of Norwegian friends so 23 24 I went to Norway. 24 25 MS FRASER BUTLIN: But while you were there you had a road 25 49 1 MS FRASER BUTLIN: You were treated at Haukeland Sykehus 1 2 2 in Bergen; is that right? MR ANDREW BRAGG: Correct, yes. 3 3 4 MS FRASER BUTLIN: You were then transferred back to 4 5 5 Liverpool. 6 MR ANDREW BRAGG: Yes, I was flown home. I had a night at 6 7 7 home. The GP came out to see me because the 8 Norwegians just gave me one day's worth of drugs, took 8 9 9 one look at me and called an ambulance. I went to 10 10 Broadgreen Hospital in Liverpool. Bit of a culture 11 shock. First time I had actually been on the 11 12 receiving end in a UK hospital, and compared to Norway 12 13 it was -- I will call it second world but certainly 13 14 Norway was far more impressive as a place to be. 14 15 MS FRASER BUTLIN: And when you were in Norway you were 15 16 16 given blood transfusions in Norway. MR ANDREW BRAGG: Yes. 17 17 18 MS FRASER BUTLIN: You were then in Broadgreen Hospital 18 19 for a while and then subsequently, in November 1986 19 20 and December 1986, you had further surgery. 20 21 MR ANDREW BRAGG: Yes, they needed to remove the fixings 21 22 through the tibial nail. I have no idea if I had 22 23 23 a blood transfusion in the theatre. I can't remember 24 24 having a blood transfusion when I was on the ward 25 after I came out of theatre. I was in a world of pain 25 51

MR ANDREW BRAGG: Yes, I discovered a very interesting tunnel up in the mountains near Bergen which had no lights in it and it turned right on entry so I went straight into the wall. MS FRASER BUTLIN: In terms of the injuries you sustained, can you tell us about those? MR ANDREW BRAGG: First point of contact was my head and face. Then my motorbike landed on my leg and crushed my right leg, so the estimate was I had something like 17 fractures below the knee. It was two and a half hours to extract me from my hole in the ground, get me to Bergen, but the medical treatment in Bergen was fantastic. They had a major trauma unit, so there was everybody on hand when I arrived. They stabilised me. I had an operation that night. MS FRASER BUTLIN: You had a tibial nail inserted? MR ANDREW BRAGG: Absolutely, yes. Unusual procedure at the time, but I had so many fractures to my tibia that they put a titanium nail from my knee to my ankle, and basically realigned all the fractures around it and then fixed it. MS FRASER BUTLIN: You also had fractures in your foot and ankle and they were secured with wires? MR ANDREW BRAGG: Yes. 50 so I wasn't really paying much attention to that. MS FRASER BUTLIN: The two surgeries, the first one was to remove the wires in your foot and ankle and then the December surgery was to remove the screws from the tibial nail. MR ANDREW BRAGG: Yes. MS FRASER BUTLIN: When you were there do you recall if that was considered to be quite major surgery or whether it was relatively routine? MR ANDREW BRAGG: It certainly wasn't routine. I was out for -- well, they put me out. When I came to I had a bruise from my shoulder to my groin, because -- the Norwegians had told me the screws needed to come out after eight weeks, and it was 17 weeks, so they had quite a struggle, and they had also opened up all the fractures in my tibia again, so I wasn't in great shape. MS FRASER BUTLIN: Then in October 1987 you were treated in Blackburn Royal Infirmary and they removed the tibial nail at that point? MR ANDREW BRAGG: Yes, I was getting a lot of pain in my knee, so walking was very, very painful because it was metal on bone, so it was agreed to take the nail out. MS FRASER BUTLIN: Do you know whether in that surgery you had a blood transfusion? 52

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1	MR ANDREW BRAGG: I definitely I remember coming to and	1	know what I had, so they started a very extensive set
2	seeing the bags of blood hanging up around me.	2	of tests to establish what I might have had in India.
3	MS FRASER BUTLIN: You were then readmitted two weeks	3	After about two months they said, "We can't actually
4	later because of more complications?	4	detect anything that you might have caught in India
5	MR ANDREW BRAGG: Yes. My knee swelled up really, really	5	but there doesn't seem to be something right with your
6	badly. I'd attended the fracture clinic. The	6	liver. Give it" I think it was another month and
7	solution seemed to be that the doctor got hold of my	7	they came back and said, "Here's a letter. Go to see
8	knee and pressed, so that burst all the stitches and	8	your GP. You've got hepatitis C".
9	emptied the certainly effective in draining my knee	9	MS FRASER BUTLIN: So once you were diagnosed with
10	but it meant I was readmitted.	10	hepatitis C, effectively through the tests that the
11	MS FRASER BUTLIN: That was 1987.	11	occupational health team had done, you were then
12	MR ANDREW BRAGG: Yes.	12	referred to the Freeman Hospital.
13	MS FRASER BUTLIN: How did you then come to find out you	13	MR ANDREW BRAGG: In Newcastle, yes.
14	had hepatitis C?	14	MS FRASER BUTLIN: What were you told then about the
15	MR ANDREW BRAGG: Working for ICI from in the	15	availability of treatment?
16	mid-1990s, I started working on the more international	16	MR ANDREW BRAGG : Well, they reconfirmed the diagnosis by
17	side of the business and I was working with ICI India	17	PCR and they also did a liver biopsy. So the feedback
18	to establish a business in India, so late 1998 I was	18	from that was that I definitely had hepatitis C, that
19	having a meeting in New Delhi and I became quite ill.	19	I had fibrosis to the liver. I asked them what the
20	It was about a week before I was well enough to fly	20	implications was for me and they said, "Well, based on
21	home.	21	what we have seen, you have probably got five to seven
22	That sort of passed but I felt ill. I never felt	22	years to live".
23	well again. My GP basically said, "Well, you've been	23	So obvious next question is, "What treatment are
24	in India, you have got something. It will go". But	24	you going to give?"
25	the occupational health department in ICI wanted to	25	And the answer was, "None, it is too expensive for
	53		54
1		1	ofter four menths 16 weeks I had depred Se
1	the NHS."	1	after four months, 16 weeks, I had cleared. So
2	I asked them how much it cost and they said about	2	I continued to the end.
2 3	l asked them how much it cost and they said about £20,000. I said, "Well, can I pay for it?"	2 3	I continued to the end. MS FRASER BUTLIN: Since that treatment, what's your
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1	MR ANDREW BRAGG: Yes.	1
2	MS FRASER BUTLIN: In terms of your immune system, you	2
3	went to see an immunologist about that.	3
4	MR ANDREW BRAGG: Yes, I did.	4
5	MS FRASER BUTLIN: What were you told?	5
6	MR ANDREW BRAGG: That basically there's four proteins	6
7	that form the basis of your immune system, and two of	7
8	them in my case were at very low levels. One of them	8
9	is called C-reactive it's CRP, C-reactive protein,	9
10	is what doctors use to establish whether you have	10
11	an infection or not. And the immunologist told me	11
12	that my base levels were so low that even if they went	12
13	up a hundred-fold, I still wouldn't pass the test that	13
14	a standard doctor would recognise that I had	14
15	an infection. So I have a history of knowing I have	15
16	an infection but not getting a doctor to believe me	16
17	that I have an infection. So usually I have to wait	17
18	until I get seriously ill before they'll intervene.	18
19	MS FRASER BUTLIN: What has the impact been on your work	19
20	with all of these health difficulties?	20
21	MR ANDREW BRAGG: What effectively it's done is I since	21
22	I had treatment I've not been able to do a responsible	22
23	role. So I have not been able to run a business.	23
24	I have not been able to have a team of people. I have	24
25	really not been able to manage a line budget, so	25
	57	
1	l should have a go at this.	1
2	MS FRASER BUTLIN: With your application for the Skipton	2
3	Fund, you provided a letter from Norway which you had	3
4	obtained in 2001.	
5		4
	MR ANDREW BRAGG: For the initial application, yeah.	4 5
6		-
6 7	MR ANDREW BRAGG: For the initial application, yeah.	5
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7 8	 MR ANDREW BRAGG: For the initial application, yeah. MS FRASER BUTLIN: Can we MR ANDREW BRAGG: So I was of the understanding that hepatitis C was, like, something you had to register 	5 6 7 8
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the Norwegians to tell them you had hepatitis C?

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1	effectively my career in the company came to an end
2	when I had treatment. Because, you know, if you are
3	having six, eight, ten weeks a year off sick, then you
4	are not a reliable employee. So I am more in
5	a skilled you know, so I advise the company on
6	things. But it means, you know, I've just not been
7	able to progress.
8	MS FRASER BUTLIN: I think you described that you are
9	doing a sort of technical role but you can't do any of
10	the managerial or business work that you were
11	previously doing?
12	MR ANDREW BRAGG: No.
13	MS FRASER BUTLIN: In terms of the Skipton Fund, can you
14	tell us how you came to hear about it?
15	MR ANDREW BRAGG: Through The Hepatitis C Trust. One of
16	the things that I did carry on after I was discharged
17	from Newcastle was that there was a charity called
18	Liver News which gives you booklets and informs you
19	what is going on at the Freeman, and one of the
20	articles in there was around a survey that this
21	hepatitis C Trust was doing, to which I signed up for.
22	It was looking for what was the ongoing effects of
23	treatment. And in one of the articles in one of their
24	magazines it mentioned the Skipton Fund, which I had
25	never heard of. So I looked it up more and thought
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1	MR ANDREW BRAGG: Yes.
2	MS FRASER BUTLIN: We see their response:
3	"I am sorry to hear that you have got the
4	diagnoses hepatitis C. During your hospital stay in
5	Bergen you received blood from 4 donors. The
6	Haukeland University Hospital Bloodbank started
7	hepatitis C-testing in October 1990. In 1986 the
8	hepatitis C virus was unknown and consequently there
9	was not any test available.
10	"We have examined through our donor files. Three
11	of the four donors have tested anti-hepatitis C
12	negative. The fourth donor has not given blood since
13	1987, and she has not tested hepatitis C positive as
14	a patient."
15	So you sent this letter with your application to
16	the Skipton Fund but your application was refused.
17	MR ANDREW BRAGG: Yes.
18	MS FRASER BUTLIN: If we can turn to that.
10 19	EIBS0000148, please, _061.
	LIDS0000140, please, _001.
20 21	We see a response if we look down towards the middle of the page:

"The supporting medical information submitted in your application did not provide sufficient evidence that ..."

On the balance of probabilities that you had 60

25

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1 contracted hepatitis C through NHS blood or blood MS FRASER BUTLIN: You also obtained a further letter from 1 2 2 products. the Norwegian Hospital Trust. 3 3 "I understand from the documentation provided that MR ANDREW BRAGG: Well, I got in touch with the Norwegians 4 you received blood transfusions from four donors in 4 to tell them what EIBSS had said. 5 Norway and three of the four donors were Anti-HCV 5 MS FRASER BUTLIN: We have got their response, the 6 negative but the fourth cannot be ruled out as 6 Norwegian response. 7 a potential source of infection. The medical 7 WITN0195002, please. 8 8 Dated April 2018. Is this the response that you assessors could find no record of your receipt of NHS 9 blood or blood products in the documentation 9 got? It says: 10 10 provided." "This is a response to your letter of March 20th 11 You sought your records from Blackburn Hospital. 11 2018 concerning further information on the donor about whom we had no definite information about hepatitis C 12 MR ANDREW BRAGG: I did. 12 13 MS FRASER BUTLIN: What were you told about that? 13 status in 2001. MR ANDREW BRAGG: I had a letter saying that, in 14 "She has now been repeatedly [I think it should 14 15 accordance with hospital policy, my records had been 15 say 'tested'] for antibodies to hepatitis C in 16 16 relation to multiple hospital visits since 2005, all destroved. 17 MS FRASER BUTLIN: And in relation to Broadgreen Hospital, 17 tests for anti-HCV have been negative. 18 what notes did you get from them? 18 "As mentioned in the letter from prof Hervig in 19 MR ANDREW BRAGG: They sent some records. I wouldn't 19 2001 the other three donors of the 4 units of blood 20 describe them as comprehensive but they had actually 20 you received in 1986 were repeat donors beyond our 21 something on file. But it was quite difficult to 21 testing for hepatitis C and testing negative. 22 really establish in detail what had happened. 22 "It is highly unlikely that you have contracted 23 MS FRASER BUTLIN: And in those records there wasn't any 23 hepatitis C from the transfusions in 1986." 24 indication of a blood transfusion in those records? 24 So, you provided that to EIBSS. 25 MR ANDREW BRAGG: No. 25 MR ANDREW BRAGG: Yes. 61 62 MS FRASER BUTLIN: And appealed their decision. If we can 1 1 records have been destroyed. I was admitted for 2 2 look at your appeal email. surgery to remove the tibial nail from my right leg on 3 EIBS0000148_064, please. 3 12th October 1987 and had the operation the following 4 We can see there that you had provided the three 4 day. The date is very clear to me because my step 5 5 responses, the Haukeland Sykehus Bergen response, the father had a heart attack at the hospital after 6 Royal Liverpool Hospital's response and the East 6 dropping me at the ward. I was allowed out of bed for 7 7 Lancashire Hospital response, and then you wrote this: the fist time to visit him on October 23rd. He died 8 "It is very disappointing that East Lancashire 8 that evening. I was readmitted to BRI a week later 9 9 trust has destroyed my records because I had following complications with my right knee. 10 10 a significant operation to remove the tibial nail at "Contracting hepatitis C has been a major event in 11 Blackburn Royal Infirmary in 1987. This surgery was 11 my life which has severely impacted on my health, 12 followed by readmission to deal with the complications quality of life and work prospects. I am sure that 12 13 which followed. 13 this was contracted during one of the medical 14 "A summary of my case for inclusion in the EIBSS 14 procedures I underwent during treatment within the UK. 15 scheme was that: 15 On this basis I am appealing your earlier decision." 16 "1. The Norwegian authorities have extensive 16 That appeal was unsuccessful and we will just, if 17 records of my treatment and all blood donors involved 17 we may, turn to the rejection of the appeal. 18 and they believe that it is highly unlikely that 18 WITN0195006. 19 I could have contracted Hepatitis C during their 19 There are the standard provisions -- standard 20 20 treatment. letter on the first page, but if we turn to page 2, 21 "2. I had two surgical procedures in Broadgreen 21 and it is the third paragraph: 22 Hospital in Liverpool in 1986 for which some limited 22 "The Panel noted that your appeal was based on 23 23 records are available and are attached. a transfusion you received on returning home following 24 24 "3. I had one major surgical procedure in a road traffic accident in 1986 in Norway. 25 Blackburn Royal Infirmary in 1987 for which all 25 Unfortunately, due to the lack of supporting evidence 63 64

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1 including medical records confirming that you were 1 about it until I saw the record. She did tell me that 2 2 she had an accident. But she was not eager to sort of treated with NHS blood or blood products prior to 1991 3 3 in England, the Panel were not satisfied that it was explain anything. She was still a bit sad about it, 4 more probable than not that your Hepatitis C infection 4 so she didn't and I didn't press on it, but I knew she 5 resulted from qualifying NHS treatment. Accordingly 5 had an accident where she had a very terrible time in 6 we regret that we must refuse your appeal." 6 the hospital. 7 Andrew, were there any more records that you could 7 MS FRASER BUTLIN: In your statement you've said that she 8 have obtained? 8 had an operation to have her spleen removed and part 9 MR ANDREW BRAGG: Not that I was aware of. I would have 9 of her stomach removed. 10 pursued it if I thought I could find more evidence. 10 MS RUBY GILKES: Yes. 11 It doesn't help that the system is guite diffuse, 11 MS FRASER BUTLIN: And your understanding is that she had there is no clear pathway of how to obtain this 12 12 multiple blood transfusions at that point in time? 13 evidence, so it's quite difficult and challenging to 13 MS RUBY GILKES: At that time, yes. 14 be outside of the system and then try and find it. 14 MS FRASER BUTLIN: And through them she contracted 15 MS FRASER BUTLIN: I think that's something we will come 15 hepatitis C? 16 back to in our thematic conversation shortly. MS RUBY GILKES: Yes. 16 17 If we could then turn, Ruby, to talk to you 17 MS FRASER BUTLIN: And also suffered renal failure and 18 a little bit about your situation. You are here to 18 required a kidney transplant in 1989? 19 19 MS RUBY GILKES: Yes. speak about your late sister, Anne, Ruby? 20 She had a road traffic accident in 1982; is that 20 MS FRASER BUTLIN: And in 1999 Anne was told she had 21 21 contracted hepatitis C but the family weren't aware of right? 22 MS RUBY GILKES: Yes. 22 that at the time; is that right? 23 MS FRASER BUTLIN: And she sustained some very serious 23 MS RUBY GILKES: No, we weren't aware of it. I just 24 injuries in that accident? 24 happened to saw when I was -- after she died and I was 25 25 MS RUBY GILKES: According to the record, I didn't know cleaning the house out, that I came across all the 65 66 1 details of it. 1 me. And so she gave me the telephone number of the 2 2 MS FRASER BUTLIN: In 2003 Anne developed rectal cancer as hospital, so I called the hospital the day and the 3 well. 3 doctor -- the nurse that was attending in ICU 4 MS RUBY GILKES: Yes. 4 confirmed that, yes, Anne was unconscious at the time. MS FRASER BUTLIN: She was also diabetic. 5 So just during the time I was ringing they never 5 6 MS RUBY GILKES: She was a diabetic. After the transplant 6 called me to find out what -- or give me any 7 7 information, so I had no information. she got diabetes. 8 MS FRASER BUTLIN: And in 2007 her transplanted kidney 8 MS FRASER BUTLIN: Anne had septicaemia? 9 9 began to fail; is that right? MS RUBY GILKES: She contracted septicaemia and she also 10 MS RUBY GILKES: It would be 2006. Yes. 10 had a stroke. 11 MS FRASER BUTLIN: Then in February 2007 I think you 11 MS FRASER BUTLIN: And she also had bleeding in the colon 12 received a telephone call from her neighbour? 12 as well. 13 MS RUBY GILKES: Her neighbour, yeah. 13 MS RUBY GILKES: She was ...? 14 MS FRASER BUTLIN: At that point you were in Barbados? 14 MS FRASER BUTLIN: Her colon, there was bleeding in her 15 MS RUBY GILKES: I was in Barbados. I did missionary work 15 colon, in her lower intestine. 16 there for the church. 16 MS RUBY GILKES: Yes, she had serious bleeding in the 17 17 colon, that's it. MS FRASER BUTLIN: What was the situation with Anne, what 18 had happened with her? 18 MS FRASER BUTLIN: You got back to the UK in March, not 19 MS RUBY GILKES: Well, the neighbours who called me and 19 very long after that, and you found Anne was really 20 told me that the taxi that takes her to the unit for 20 very unwell at that point? 21 the -- renal unit -- and that the taxi man could not 21 MS RUBY GILKES: Well, she was very unwell. I spent 22 get into the house. So he called a neighbour and the 22 three days with her. On Monday I got back from 23 23 neighbour of course had the keys and she went in and Barbados, the earliest flight I could get back, and 24 24 her words were, to me, they found her on the floor I spent Monday, Tuesday and Wednesday in Norwich and 25 unconscious in a pool of blood. That was her words to 25 I told her I would come back because she was telling 67 68

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1	me about that they were going to do an operation on	1	that a message from the hospital chaplain to say that
2	her and her words were they were going to bring part	2	under no circumstances to see the body, to view the
3	of her belly out on the top and she said to me,	3	body.
4	"I never I could never live with that. I could	4	So we left the hospital and the time came and we
5	never live with that. No, no, I could never". So	5	were then I went to register the death. I never
6	anyhow, to start a story, I told her I would come back	6	even looked to see and didn't even realise I gave the
7	on the next week, the Monday, and see the doctor	7	wrong the lady said, "Clark with an e", and to be
8	because up until then I had no communication with the	8	quite honest I was I just thought she wrote,
9	hospital, nothing. So I told her I would come back on	9	I think she wrote Clark without the e.
10	the Monday and see her.	10	Anyhow, the time came for her to be buried and
11	And, unfortunately, on the Monday I was we	11	I went then to the funeral director and I took her
12	went I came back, on the coach again, and it was my	12	best clothes because she was a model. She used to
13	daughter and my sister, and I got a telephone message	13	model these clothes and catwalk. She was very
14	to say that my Anne was taken to the operating	14	independent and she was very winning.
15	theatre the night and that she unfortunately, they	15	So I took a very nice dress and say you know.
16	couldn't stop the bleeding and they let her go. She	16	Then they told me, no, that, you know, it was no use
17	died.	17	to bring that because under no circumstances the
18	So we still carry on, the three of us, to the	18	hospital said to view the body.
19	hospital. We got to the administrative office and by	19	MS FRASER BUTLIN: Anne had undergone an operation to fit
20	the time we go into operation the office, saw the	20	a colostomy bag. So it was to have
21	nurse sitting there and she told me, she never even	21	MS RUBY GILKES: Yes, a colostomy bag on the outside, you
22	said no sorry, nothing. She just said give us	22	know.
23	the belongings to Anne and she gave the certificate	23	MS FRASER BUTLIN: A stoma.
24	and whatever. I never even looked at it because the	24	MS RUBY GILKES: I didn't discuss it with her but I was
25	shock of it. But what she said is then she told me	25	going back on the Monday to see the after she told
	69		70
1	me and she was so determined, she said, "I will never	1	told you". I said, "No, she never told me anything
2	have that. I will never have that. No, I can't live	2	about it but I got the record that, you know, that you
2 3	have that. I will never have that. No, I can't live with that", and I said I would go back on the Monday	2 3	about it but I got the record that, you know, that you sent, and I got the information from you that that's
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1	troated your sister had ratired; is that right?	1	"IL End stage Renal failure, Disbetes, Henstitis
1 2	treated your sister had retired; is that right? MS RUBY GILKES: Yes.	2	"II End stage Renal failure, Diabetes, Hepatitis C, Carcinoma Rectum, Sarcoid Liver."
3	MS FRASER BUTLIN: So the form was completed by	2	Because the death certificate didn't say that
4	a clinician on the basis of the records they had but	4	liver failure had caused her death then the
5	had never treated Anne?	5	application for a stage 2 payment was refused; is that
6	MS RUBY GILKES: No, that's what it said. He never	6	right?
7	treated Anne, he didn't know Anne but that's what the	7	MS RUBY GILKES: That is correct.
8	record says so he	8	MS FRASER BUTLIN: But you have sought to challenge the
9	MS FRASER BUTLIN: He sent the form as Skipton required	9	death certificate?
10	directly to Skipton?	10	MS RUBY GILKES: Sorry?
11	MS RUBY GILKES: Yes.	11	MS FRASER BUTLIN: You weren't happy with what was put on
12	MS FRASER BUTLIN: But that meant you didn't see what he	12	the death certificate?
13	had written?	13	MS RUBY GILKES: No, at that point I looked at it because
14	MS RUBY GILKES: I didn't see what he write, no.	14	I didn't see before that I didn't observe the death
15	MS FRASER BUTLIN: And you had concerns about what he	15	certificate. But at that point, after he said that,
16	might have written?	16	you know, what was written on the death certificate
17	MS RUBY GILKES: Yes.	17	wasn't the criteria of what he wanted, I looked at it
18	MS FRASER BUTLIN: If we can look at if you are	18	and then I saw, no, that is what they have there
19	comfortable with this, look at Anne's death	19	for the cause of death is not really what happened.
20	certificate.	20	And also I said you know, I write to him and I told
21	WITN0805008, please.	21	him that. It wasn't like that. It wasn't she had
22	We have towards the just below halfway, the	22	an operation that caused her death. So he didn't
23	cause of death is marked as:	23	agree, doesn't agree with it. He just doesn't.
24	"I(a) Lower Gastrointestinal bleed.	24	MS FRASER BUTLIN: You have sought to you have made
25	"(b) Angiodysplasia of colon.	25	a complaint to the Parliamentary Ombudsman?
	73		74
4			and you know what have an adduction the exception. Co
1	MS RUBY GILKES: Yes.	1 2	out, you know, what happened during the operation. So
2 3	MS FRASER BUTLIN: But that wasn't upheld? MS RUBY GILKES: What they say, they did an investigation,	2	I told them told Mr the Skipton Fund that I did not agree with what they were saying, as he was trying
4	they say. In paragraphs they said in one paragraph	4	to convince me that she died of problems with her
5	they said that she did acknowledged that she had	5	intestines. I told him no, it is not so.
6	been to the operating theatre on 12 March. And then	6	MS FRASER BUTLIN: Thank you. We can take that down.
7	further down into another category they said that	7	Peter. You work as an architect.
, 8	she that Mrs Anne Jordan-Clarke sadly died in	, 8	MR PETER FRITH: I'm a chartered architect, yes.
9	hospital on 6 March. So that caused two deaths: she	9	MS FRASER BUTLIN: During your training in August 1974 you
10	had one on the 12th and one on the 6th. So they	10	were on a work placement when you had a
11	didn't agree with me that, you know they were not	11	MR PETER FRITH: Yes, it's actually I put that down
12	in agreement with me at all. They didn't do anything	12	it is actually April.
13	about it.	13	MS FRASER BUTLIN: April 1974, apologies.
14	MS FRASER BUTLIN: I think you have tried to challenge the	14	You were on a work placement when you had
15	death certificate because you feel that hepatitis C	15	a nosebleed.
10			
	played a more significant part in your sister's death	16	MR PETER FRITH: That is correct.
15 16 17	played a more significant part in your sister's death than we see here, particularly in relation to the	16 17	MR PETER FRITH: That is correct. MS FRASER BUTLIN: That wouldn't stop?
16	than we see here, particularly in relation to the		MS FRASER BUTLIN: That wouldn't stop?
16 17		17	
16 17 18	than we see here, particularly in relation to the gastrointestinal bleed, is that right?	17 18	MS FRASER BUTLIN: That wouldn't stop? MR PETER FRITH: It wouldn't stop, yeah.
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1	of hours and it seemed to be under control and I was	1	MR PETER FRITH: Yes. I received blood before and after.
2	discharged home later that day. I went home. The	2	MS FRASER BUTLIN: Had you seen that you were receiving
3	bleeding continued, the blood running down the back of	3	blood or is that a recollection of
4	my throat. My mother called an ambulance and I was	4	(overspeaking)
5	readmitted and I was admitted onto the ENT ward at	5	MR PETER FRITH: Yes, when I was admitted to the hospital
6	North Lonsdale Hospital. I was there under the ENT	6	because I had been losing so much blood I can recall
7	consultant, Mr Potter. Kept in bed, still, not to	7	them putting the drip in my arm. Because I am very
8	move until the blood had stopped. He then took me	8	adverse to needles.
9	I can't recall the exact sequence of events on that	9	MS FRASER BUTLIN: In the autumn of 1975 the nose bleeds
10	particular instance but I think I was taken down for	10	recurred again.
11	an investigation and they determined I had a fibroma	11	MR PETER FRITH: They did.
12	of some sort and felt it would, I think, at that time,	12	MS FRASER BUTLIN: And you were referred on that occasion
13	would subside.	13	to Birmingham.
14	MS FRASER BUTLIN: You were diagnosed with nasopharyngeal	14	MR PETER FRITH: Because I was in college in Birmingham,
15	angiofibroma, which is a benign tumour.	15	the GP I had in Birmingham referred me to the
16	MR PETER FRITH: Yes, that was so I went back to	16	Steelhouse Lane Hospital in Birmingham where I saw
17	college in September and the nose bleeds restarted.	17	a ENT consultant there. It so happens my previous ENT
18	I was then referred back to the ward and I was	18	consultant had issued me with a letter which
19	re-examined and the nasopharyngeal angiofibroma was	19	I don't have because it went to the hospital which
20	determined, a benign tumour.	20	had explained in case of recurrence because
21	MS FRASER BUTLIN: And you had surgery to remove the	21	apparently these tumours are prone to recurrence
22	tumour.	22	that I'd been operated on for this procedure. When
23	MR PETER FRITH: Yes.	23	I gave this to the consultants they were sort of
24	MS FRASER BUTLIN: And at that time you think you received	24	overjoyed. They had never seen this before.
25	eight units of blood.	25	MS FRASER BUTLIN: Even in Birmingham this was a very rare
	77		78
1	tumour.	1	following both operations and spent a week at the
1 2	tumour. MR PETER FRITH: Yes I was advised in Birmingham this was	1 2	following both operations and spent a week at the hospital there undergoing masses of amount of x-rays.
2	MR PETER FRITH: Yes, I was advised in Birmingham this was	2	hospital there undergoing masses of amount of x-rays,
2 3	MR PETER FRITH: Yes, I was advised in Birmingham this was a very rare tumour, one in five million.	2 3	hospital there undergoing masses of amount of x-rays, research, and at the end of which they concluded that
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1	a medical and he carried out the medical, at the end	1	a week or so later I had a phone call at the office
2	of which he said, "Everything is fine, except your	2	from my GP.
3	liver seems very enlarged". He says, "It is nothing	3	MS FRASER BUTLIN: He asked you to go straight down.
4	to worry about, what we will do is we will get you	4	MR PETER FRITH: Yes, can I go straight to his, please,
5	referred to a consultant and see what we can find	5	"Tell the receptionist I phoned you". I went to see
6	out".	6	him and he said, "You've tested positive for
7	Consequent to that I was referred to Gillian	7	hepatitis C", and he admitted that he did not know
8	Townsend, a consultant at the Princess Royal Hospital	8	a lot about it himself and that he had been contacted
9	in Telford. I visited her and sat there for about	9	by this consultant because she was on holiday and was
10	an hour. She took a very detailed medical history,	10	anxious that I should know straightaway.
11	asked me lots of detailed questions about my previous	11	MS FRASER BUTLIN: Take your time.
12	health and about the operations I had had. I then	12	MR PETER FRITH: Anyway, I eventually got back to see
13	went under MRI scans, ultrasound scans and lots of	13	Gillian Townsend and she explained about hepatitis C
14	blood test.	14	and most likely cause, from the history she had taken,
15	Following that, one morning a letter arrived at	15	was from the blood transfusions I had had back in 1974
16	home and it was a letter from the hospital saying,	16	and 1975.
17	"You have tested positive for HCV, we would like to	17	I was immediately transferred under the care of
18	have you back for another test just to make sure this	18	a specialist hepatitis C nurse, which they had at
19	is not a false positive". At that time, heaven knows	19	Princess Royal, a lady by the name of Sandra Taylor,
20	I didn't know what HCV stood for, so what's the first	20	who was absolutely brilliant. And I was very
21	thing you do? You go and Google HCV. And then all	21	fortunate to have had her. I didn't realise that
22	this stuff about hepatitis C comes up on the screen.	22	a lot of authorities didn't have that facility. And
23	Wife was at work. I just rang her up and said,	23	she was totally dedicated to dealing with patients
24	"I have just had this, I don't know what to think".	24	with hepatitis C, whether it be needlestick injuries,
25	Anyway, I went for the second blood test and then	25	drug addicts, whatever. And she was very good.
	81		82
1	MS FRASER BUTLIN: You underwent treatment with interferon	1	MR PETER FRITH: Yes, it does. I am very get
	MS FRASER BUTLIN : You underwent treatment with interferon and ribavirin.		MR PETER FRITH: Yes, it does. I am very get depressed, feeling of loneliness.
1 2 3		1 2 3	depressed, feeling of loneliness.
2	and ribavirin.	2	
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1	MS FRASER BUTLIN: And what were you told?	1	basis they accepted that I had not demonstrated
2	MR PETER FRITH: I was told they had no evidence. I said,	2	I had any blood products.
3	"Well, these consultants, they know what they are	3	MS FRASER BUTLIN: So you had a simple rejection because
4	talking about". So, yes, they needed physical	4	nothing had been provided. You then provided what you
5	evidence I had had an operation and had had blood	5	had and that was still rejected?
6	products.	6	MR PETER FRITH: That was still rejected.
7	So, okay, I then went away and I approached the	7	MS FRASER BUTLIN: At that point you decided to appeal?
8	North Lonsdale Hospital, which no longer existed, and	8	MR PETER FRITH: At that point I then phoned Mr Fish again
9	the subsequent hospital, the Furness District	9	to find out what I had to do and I managed to get him
10	Hospital, I rang them and spoke to their records	10	to admit what I had to do was I had to prove that it
11	department and the first thing they asked me was,	11	was probable that I had had blood products during
12	"You're not making a claim against us, are you?"	12	these operations, so that's what I set out to do.
13	I subsequently got a letter from them saying there	13	MS FRASER BUTLIN: Can you tell us, first of all, I think
14	were no records. They had been destroyed.	14	one of the things you did was sought a private ENT
15	MS FRASER BUTLIN: The Christie Hospital did provide some	15	appointment.
16	information that cross referred?	16	MR PETER FRITH: Unfortunately, the consultant I had
17	MR PETER FRITH: They did, yes, and there was limited	17	approached the consultant who did the operation but he
18	records from my GP as well.	18	had died. So I then approached I got the
19	MS FRASER BUTLIN: At that point you sought a private	19	impression that the medical people looking at my
20	consultation with an ENT	20	records didn't understand what had happened, so
21	MR PETER FRITH: No, I submitted in the first place,	21	l approached a I paid for a private consultation
22	I submitted those initial records from the Christie	22	with an ENT consultant to get an opinion on what he
23	and my GP which clearly showed that I had had	23	thought would have happened during that operation.
24	an operation for a nasopharyngeal angiofibroma	24	MS FRASER BUTLIN: Because from your perspective the
25	removal. Then that was subsequently rejected on the	25	nasopharyngeal angiofibroma was rare and it appeared
	85		86
1	that the Skipton Fund hadn't grasped	1	to specifically reduce the vascularity of this lesion
2	MR PETER FRITH: That's correct.	2	in 1974 or 1975, and therefore one would expect
3	MS FRASER BUTLIN: how vascular that area was?	3	considerable bleeding at the time of surgery both in
4	MR PETER FRITH: Yes.	4	1974 and in 1975. It would therefore seem very highly
5	MS FRASER BUTLIN: If we look at the report produced by	5	probable indeed that [you] would have required at
6	the private surgeon.	6	least one or more blood transfusions at or around the
7	SKIP0000088, and it is page 52 that I want to	7	time of both of these operations."
8	start with, please.	8	Then if we carry on to page 56, which is the
9	If we look at the last paragraph of this page we	9	second part of the letter:
10	see, we pick it up five lines down:	10	"[You are yourself] aware of blood transfusions
11	"The main treatment for nasopharyngeal	11	that occurred at that time. Equally [you are] also
12	Angiofibroma involves excision of the lesion and	12	aware that considerable operative measures were taken
13	sometimes consideration for radiotherapy. Because of	13	to reduce bleeding in this period and this included
14	the degree of vascularity of the lesion, present	14	packing of the nasal fossa anteriorly and also packing
15	treatment in 2009 would normally include embolisation	15	the nasal fossa and nasopharynx posteriorly. [You
16	using interventional radiology to achieve	16	are] aware that after the main operation in 1974 and
17	a significant reduction in the blood supply to the	17	1975, that he subsequently required a general
18	tumour, prior to considering surgery for removal.	18	anaesthetic for removal of the packing some two to
19	Despite this, the treatment for this lesion would be	19	three days following the main operation. These packs
20	highly likely to cause significant bleeding during the	20	were specifically inserted to reduce the postoperative
20	surgical procedure. It is noted however, that this	20	bleeding, which would have been very highly likely."
22	lesion was excised in 1974 and subsequently required	22	So you'd paid privately for this report?
23 24	further excision at a second operation twelve months	23 24	MR PETER FRITH: I did.
24 25	later in December 1975. I would therefore expect that	24 25	MS FRASER BUTLIN: And provided that in your appeal. You
25	no radiological procedure would have been undertaken 87	25	also obtained statements from your family members?
	07		88
			(22) Pages 85 - 88

1	MR PETER FRITH: did.	1	We have a note here of the information as
2	MS FRASER BUTLIN: Dealing with their recollections of you	2	previously submitted. Just go down and we have the
2 3	, , , , , , , , , , , , , , , , , , ,	2	
4	receiving blood. MR PETER FRITH: Yes.	4	bullet points:
4 5	MS FRASER BUTLIN: And when you	4 5	"- The Skipton Fund Application Form duly
6	-	6	completed by me and the Medical Team at the Princess Royal Hospital, Telford, overseeing my hepatitis C
7	SIR BRIAN LANGSTAFF: I just noticed in the last paragraph	7	treatment.
8	it says: " treatment of such a tumour in 1974 would	8	
			"- A letter from my Consultant and Hepatitis C
9	almost certainly have required blood transfusion at	9 10	Screening Nurse confirming their investigations on my
10 11	some stage" So that, again, is you didn't draw attention to	10 11	behalf, and that in their opinion there are no other
12	that, again, is you don't draw attention to	12	risk factors evident which would have led to me being
		13	infected by the Hepatitis C virus.
13	MS FRASER BUTLIN: Apologies, sir, you are absolutely		"- A copy of a letter from University Hospitals of
14	right. There is that reference.	14 15	Morecambe Bay, which confirms that the records of my
15	When you appealed you provided all of that, and	15	operations carried out at North Lonsdale Hospital have
16	lots of articles about the condition, running to about	16	been destroyed.
17	72 pages? MR PETER FRITH: I did. I would have provided more if	17	"- A copy of a letter from my current GP, which confirms that from the records available to him and to
18	•	18	
19	I could have had access to the medical websites which	19	the best of his knowledge I have not had any other
20 21	I couldn't get access to. I was determined, if I was	20 21	surgical procedures since the above dates." Then a note of the correspondence. That is what
21	going to go back, I was going to prove that I had	21	•
22	blood products. MS FRASER BUTLIN: Just to give a flavour of what you	22	you previously submitted. MR PETER FRITH: Yes.
23 24	provided to the appeal panel, if we could turn to	23 24	MS FRASER BUTLIN: If we turn the page we have the
24	page 24 of this document, please, Lawrence.	24	additional information supplied in support of the
25	page 24 of this document, please, Lawrence. 89	25	
1	anneal	1	the web based provision that all doctors can access
1	appeal: "- A copy of my medical records from the Christie	1	the web based provision that all doctors can access. Having compiled the 72-odd pages you provided that
2	"- A copy of my medical records from the Christie	2	Having compiled the 72-odd pages you provided that
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1 cleared -- got PCR saying cleared, discharged. There 1 2 2 was no support. There was no communication. There 3 3 was no ongoing testing. So there was almost like you 4 don't -- so, really, given the severity of hep C, 4 5 given the severity of the treatment, that it would 5 6 have been far more useful if there had been some 6 7 continuity of care post-treatment and part of that 7 8 8 should have been the Skipton Fund. 9 MS FRASER BUTLIN: Robert, I think you were agreeing with 9 10 10 that? MR ROBERT BAMFORTH: Well, yes, because I was going to 11 11 King's College Hospital for years, and then suddenly 12 12 13 they said, "Oh, you are cured, good-bye", and it was 13 14 like, hang on, this can't happen. This is part of my 14 15 life. I have been going here for donkey's years and 15 16 suddenly they have just said, "That's it, you're 16 17 finished", and it is just very -- it's like | said, 17 18 there is no follow-up. I do get my doctor to check me 18 19 but I have to get him to check me. He doesn't -- no 19 20 doctors check you. I have to say to him -- I went for 20 21 a blood test the other week and I had to say to them, 21 22 "Are you doing hepatitis C", and she says, "I haven't 22 23 got it on here". I says, "Can you get it on there", 24 and she's got it -- I haven't got the results yet but 24 25 25 I think I'm all right. 93 MR GARY MCKELVEY: Okay, retrospectively, yeah, for 1 1 2 2 someone to have said, "Look, here are some options. This is what's happened. You know, we believe, as we 3 3 4 were told, the possible cause was the blood that was 4 5 5 given in 1981. Here's a route to at least getting 6 some help of some description". 6 7 7 MR PETER FRITH: I don't think -- I was very fortunate in 8 that my nurse immediately flagged the Skipton Fund, 8 9 9 but my GP didn't know anything about it, so whether it 10 is well known, it was flagged across the National 10 11 Trust(sic) as a whole or it's only a certain few 11 12 people who were dealing with hepatitis C or -- might 12 13 have known about it, and perhaps it needs to be more 13 14 commonly aware. Because my GP didn't really 14 15 understand what hepatitis C was and that's 2009. 15 16 MS FRASER BUTLIN: And they couldn't assist either on the 16 17 Skipton Fund if they didn't understand what 17 18 hepatitis C was? Would that be fair? 18 19 MR PETER FRITH: That would be fair, yeah. I even went 19 20 back to him after my diagnosis and told him about it 20 21 and he said, "Oh, perhaps I should get tested because 21 22 I had a blood transfusion in ..." 22 23 23 MR ROBERT BAMFORTH: How come somewhere like King's 24 24 College that was doing the trials, it was the only 25 place doing the trials at first, how come they didn't 25 95

MS FRASER BUTLIN: And part of that follow-up should, you think, have included discussion about the Skipton Fund and support to apply? MR ROBERT BAMFORTH: Yes. MS FRASER BUTLIN: Gary, do you have any thoughts on that? **MR GARY MCKELVEY:** I think in my particular case, if we go back to 1991, I'm guessing it didn't exist but it was a case of father dies on the Saturday, come to hospital on the Sunday, it was my signature on the death certificate, yeah, and go home. We were given no advice, support of any description. It was just -- it's you -- yeah, "Move on, get on with your life", yeah. But maybe it was very, very early days and there wasn't the understanding and recognition of -- well, I don't believe hepatitis C was even -- it was non-A, non-B at the time, is my understanding. MS FRASER BUTLIN: But given that you had been issued with a death certificate that indicated hepatic failure and viral hepatitis, what follow-up would you have expected in relation to the Skipton Fund for a bereaved family? 23 MR GARY MCKELVEY: At that time? MS FRASER BUTLIN: What would you have wanted, either at the time or once the fund was set up? 94 say? I mean, they must have known. How did they not know about the Skipton Fund and say to you, "Well, get in touch with this" -- it was only because my sons knew someone who'd done it. It is just -- I think the Skipton Fund is to not pay money out rather than to pay money out. I think the Skipton Fund was set up to save them money, not to pay out. MS FRASER BUTLIN: Andrew? MR ANDREW BRAGG: I'm not sure, if hepatitis C had been registered as a communicable disease, then they would have had central record keeping and then that would have actually enabled them to track and follow those members of the population who they were aware of had contracted it. That then would have allowed them to follow up at a later stage when the Skipton -- who they needed to approach and be proactive about it. It is not proactive. You had to find out about it and approach them. Which is the wrong way to do it, I think. MS FRASER BUTLIN: When you received the rejection letters from the Skipton Fund in various ways, can you first of all tell us the impact of those rejections on your own mental well being? MR PETER FRITH: It is devastating really, you are not lying to them. You are telling the truth and you have 96

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1 the back up of the consultant and the hep C nurse and MS FRASER BUTLIN: Because you'd provided that very 1 2 2 lengthy statement and had it all sworn. they say, "No, it's not true, it didn't happen", and 3 3 on top of the diagnosis it is just soul destroying, it MS RACHAEL TERSTEEG: Yes. 4 really is. And on the family as well. I was going 4 MS FRASER BUTLIN: So when the rejection letter came in, 5 forward to treatment, and I was being told that, 5 how did that make you feel? 6 "There is a possibility you could not be working next 6 MS RACHAEL TERSTEEG: I think the word that you used, was 7 year, but there is this possible payment that would 7 it -- you know, devastated. You put so much -- it's 8 help you". Now, that's -- what do you do? 8 all true. You put your whole self into the statement 9 MR ROBERT BAMFORTH: I think it is when you get rejected 9 and then for it to be rejected, not believed, just 10 it is like, "You are dirty, because you must have got 10 really, really hard. it some other way". That's what I think is the main MR PETER FRITH: There is a bit of hope, isn't there? 11 11 MS RACHAEL TERSTEEG: Yes. 12 thing. It's nothing to do with the money. It is to 12 13 do with the fact you've been rejected to say that you 13 MR PETER FRITH: You hope and then that's taken away from 14 got it through that. I think that's what it is. 14 you, that you are going to get some help, and it's 15 15 No -- well, it is as good as saying, "Well, you got it taken -- the carpet is taken out from under your feet 16 some other way", like the blood transfusion people 16 about that and you've got to go back to square one. 17 said, you know, which was rubbish. 17 MS RACHAEL TERSTEEG: Yes. 18 MS FRASER BUTLIN: Rachael, do you have any reflections on 18 MS FRASER BUTLIN: Andrew, do you have anything you want 19 19 that? to add? 20 MS RACHAEL TERSTEEG: I think with the Skipton Fund we 20 MR ANDREW BRAGG: It didn't really impact my mental 21 were looking to the Skipton Fund as something as 21 health. I was outraged because it was so difficult 22 a support and actually it turned out that it wasn't 22 to -- you know, when the system destroys my medical 23 a support at all. We had to fight so hard and felt 23 records, how do you expect me to prove -- and what 24 more like victims instead of people who had, yeah, 24 it -- is it not surely that it was for the Skipton 25 been infected by the hepatitis C. 25 Fund to disprove that the NHS gave it to me, not for 97 98 1 me to prove that the NHS -- they had it the wrong way 1 everyone is following process and it is not the 2 2 round. So the thing that upset me was that implied in individuals that are -- at whatever sort of 3 this was that the NHS had not given it to me and 3 organisation you are speaking with, but they just 4 therefore that I had contracted it by some other 4 repeat. And I can see it also in the documentation 5 5 route. Did they think it was an intravenous drug that you showed for everyone pretty much. It was 6 user? That really annoyed me. 6 a standard text. Yeah? It is like, "Okay, we will 7 7 MS FRASER BUTLIN: Robert, I think that's what you were just churn it out again". And we will maybe -- but 8 saving as well? 8 nothing was -- they didn't make you feel that, you 9 MR ROBERT BAMFORTH: That's what I said, yeah, yeah. If 9 know, there was anything personal involved or there 10 10 was any care. It was just standard, put it out there they're saying you haven't got it there, and they 11 reject you, they're saying that you've got it through 11 and -- okay, in Peter's case, he, you know, 12 sex or drugs or sharing needles, which -- and everyone 12 demonstrated it is possible with a lot of effort, but 13 else would think that of you because you've been 13 I don't think everyone has the time or maybe the 14 14 desire that he had, yeah, to make that happen. And, rejected. 15 MS FRASER BUTLIN: In terms of those records not being 15 you know, at the end, as Robert said to me earlier, he 16 available, and lack of documents, what are your 16 has other issues, if it is okay to mention, yeah, with 17 thoughts, collectively, individually, about how the 17 dyslexia, so it makes things very, very difficult. We 18 system should operate if there are no records? 18 are not all the same. And they should be making it 19 MR GARY MCKELVEY: Well, clearly the system doesn't 19 easier not more difficult, and it appears that the 20 20 operate. That's a fact. I was really impressed with barriers are constantly put in front of you. It 21 Andy providing records from Norway going back to 1986, 21 shouldn't be that way. 22 yeah, and if he can do that, you know, with Norwegian 22 MR PETER FRITH: Very impressed with the -- by what the 23 health authorities, it makes ours look pretty poor 23 Norwegians were able to provide. Not only that they 24 relative to that. We should be doing much better. 24 had the blood, they could identify the people it came 25 And it is just a total -- not a cop out, but I know 25 from. Compared to the brief notes and the scratchy 99 100

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1 scrawl on some of the stuff I managed to retrieve 1 2 2 is -- then why we ever choose to destroy -- I know 3 3 they are paper and they take a lot of space, but it is 4 so critical for people to be able to track their 4 5 health records for this very purpose. 5 6 MR ANDREW BRAGG: What is the purpose of medical records? 6 7 7 You know, it appears to me that here is a system 8 8 which, at best, is ill defined. It doesn't appear to 9 be auditable, because when you look at the 9 10 documentation, it is so badly filled in and so 10 11 perfunctory filled in, you get the feeling that people 11 12 are just going through the motions of ticking boxes 12 13 and throwing a piece of paper in the file, and there's 13 14 never any follow-up. You know, has the NHS ever 14 15 15 audited its medicals? I know there are better 16 procedures now in terms of what they are supposed to 16 17 do, but it is a bit late now, isn't it? 17 18 MS FRASER BUTLIN: Andrew, you come at this from 18 19 19 a particular regulatory perspective, as a chemical 20 engineer. Do you want to add any reflections from 20 21 your own professional life in terms of audit and 21 22 records? 22 23 MR ANDREW BRAGG: I work in an industry which is high 23 24 hazard. So, you know, as part of our routine 24 25 operations, we put our people at risk and we put our 25 101 1 and I haven't worked on an aeroplane for years but 1 2 2 everything I made, every rivet I used, every piece of 3 metal I used, is registered, written down, and they 3 4 could find out -- if a plane came out of the sky 4 5 5 tomorrow and I'd made a part for it, they would know 6 I made that part for it, and I haven't made parts for 6 7 7 years. Well, if they can do that on a rivet -- I 8 mean, I think I'm a bit more important than a rivet! 8 9 9 Do you know what I mean? It is every nut and bolt on 10 10 a plane is registered, right down, and forever. It is 11 never -- you know, a window come out of a plane a few 11 12 years back and they knew where the screws come from. 12 13 They could trace every -- and they pulled every 13 14 aeroplane that had screws from that batch in to be 14 15 re-checked. Well, if they can do that, why can't they 15 do it with -- for our health? You know ... 16 16 MR GARY MCKELVEY: More of a question from my side, in 17 17 18 most of the responses here we talk about records 18 19 destroyed after eight years, after ten years; is that 19 20 still the policy? 20 21 MS FRASER BUTLIN: The Inquiry heard a fairly lengthy 21 22 presentation a couple of weeks ago about medical 22 23 23 records retention. The answer is, it depends when and 24 24 where. But I can provide that to you after today. 25 Just thinking a little bit more about the 25 103

neighbours at risk and -- we transport chemicals round the world and we have to make sure we do it safely. And we have systems and procedures to make sure we do just that. But if we ever get it wrong, then we will be audited by regulatory authorities and it will not be a gentle process. It will be very ruthless and it would be determined to find the facts. So I use as an example in work that, in terms of record keeping, you must always think that you were -- if something goes wrong, somebody who is very, very rigorous, who is very well trained is going to go through this and pick out where you are at fault, so you always have to follow your procedures through with the thought that you would be audited. Now clearly some of that is internal, we have to make sure we do it, but it appears to me the NHS does not have that regulatory oversight. And that is amazing, that something which -- you know, they have a very difficult job to do in terms of managing people's health, but equally they have the ability to be detrimental to people's health if they don't do it right. You know, they are not a learning organisation. Nothing I have seen in my encounters with the NHS would encourage me to think that they learn from their mistakes. MR ROBERT BAMFORTH: I have worked in the aircraft hanger 102 Skipton Fund. In the context of the NHS and the records challenges that there were, what do you think that the Skipton Fund should have done when they were facing applications from people who couldn't provide those records because they had been destroyed? MR ANDREW BRAGG: They should have made some allowance for it. I mean, they'd be paid to use it as an excuse to reject rather than something which they needed to include in their deliberations, so it was a convenience to allow them to reject people. MS RACHAEL TERSTEEG: Yes, they didn't take any notice of witness statements. And it was such an isolating period to go through, of no contact with other people who had got the hepatitis C virus, say, a feeling of being sort of victimised and the stigma around having the illness, it's -- yes, it was awful. I think the Skipton Fund didn't seem to really be there to say -for us; it was there to protect the government. MR ROBERT BAMFORTH: Yes. MR PETER FRITH: I felt it should have been more proactive, and it should have undertaken -- I understand it needed to have rigour and, I think, a more friendly response whereby, "Yes, we've noted you have been diagnosed with -- we need to sort this information out, let us help you to try and sort this 104

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1	out. We may come to a conclusion that you are not	1
2	entitled but let us help you", and undertake you	2
3	know, the rigour I went through to demonstrate it,	3
4	I shouldn't have to do that. And I think that all	4
5	should have been support for me or point me in the	5
6	direction where I need to go, or, "We will contact	6
7	you tell us the name of the hospital, we will contact	7
8	the hospital".	8
9	MR ANDREW BRAGG: Where did the burden of proof lie? It	9
10	felt to me that I had to prove myself innocent.	10
11	Whereas, in the balance of probabilities, that should	11
12	have been taken I felt almost like the victim in	12
13	this. That, you know, I had contracted this disease	13
14	and and yet there was no sympathetic reception to	14
15	that. There was no trying to understand the balance	15
16	of where I might have got it. I can understand the	16
17	need to, you know, look at all the possibilities, but	17
18	overwhelming for me the probability is that I know	18
19	where I got it. And yet that didn't fall into the	19
20	review.	20
21	MS FRASER BUTLIN: Within some of your answers there is	21
22	a sort of mention of the attitudes and the	22
23	communication within Skipton being a challenge, and	23
24	Gary, you picked up the point about the standard	24
25	letters. What are your reflections on the	25
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1	label on that she was a high risk case, and nobody	1
2 3	told me anything, nobody I went there. No-one told	2
3 4	me she was a high risk according to the notes and	3
4 5	nobody said anything. And then some of the when	4
6	they gave me the notes because Lasked them for the	4
	they gave me the notes because I asked them for the	5
	history, the medical history after Skipton Fund keep	5 6
7	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the	5 6 7
7 8	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those	5 6 7 8
7 8 9	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing.	5 6 7 8 9
7 8 9 10	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the	5 6 7 8 9 10
7 8 9 10 11	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes	5 6 7 8 9 10
7 8 9 10 11 12	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing.	5 6 7 8 9 10 11 12
7 8 9 10 11 12 13	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me,	5 6 7 9 10 11 12 13
7 8 9 10 11 12 13 14	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the	5 6 7 8 9 10 11 12 13 14
7 8 9 10 11 12 13 14 15	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes	5 6 7 8 9 10 11 12 13 14 15
7 9 10 11 12 13 14 15 16	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were	5 6 7 8 9 10 11 12 13 14 15 16
7 9 10 11 12 13 14 15 16 17	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund,	5 6 7 8 9 10 11 12 13 14 15 16 17
7 8 9 10 11 12 13 14 15 16 17 18	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund, after, they keep telling me, "When you get the right	5 6 7 8 9 10 11 12 13 14 15 16 17 18
7 8 9 10 11 12 13 14 15 16 17 18 19	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund, after, they keep telling me, "When you get the right information then you can come back to us". And I went	5 6 7 8 9 10 11 12 13 14 15 16 17 18 19
7 8 9 10 11 12 13 14 15 16 17 18 19 20	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund, after, they keep telling me, "When you get the right information then you can come back to us". And I went to the register of the death you know, registering	5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
7 8 9 10 11 12 13 14 15 16 17 18 19 20 21	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund, after, they keep telling me, "When you get the right information then you can come back to us". And I went to the register of the death you know, registering the death, and I told them what had happened and they	5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21
7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund, after, they keep telling me, "When you get the right information then you can come back to us". And I went to the register of the death you know, registering the death, and I told them what had happened and they said, "Well, you have this", they sent me a form and	5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22
7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund, after, they keep telling me, "When you get the right information then you can come back to us". And I went to the register of the death you know, registering the death, and I told them what had happened and they said, "Well, you have this", they sent me a form and to fill out the form. But they said the form had to	5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23
7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22	history, the medical history after Skipton Fund keep rejecting the application, and I was amazed at the dates. You know, from the date she came in, all those dates were missing. The dates were missing. She came in on the 5th of the 2nd and then all the way down to the, even the ICU, some of those notes were missing. Then I saw in the same notes that they give me, one of the consultant have had sorry, to ask the registrar's one, what happened to some of the notes that he had given passed on to them. They were just missing notes. And even with the Skipton Fund, after, they keep telling me, "When you get the right information then you can come back to us". And I went to the register of the death you know, registering the death, and I told them what had happened and they said, "Well, you have this", they sent me a form and	5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22

- communication that you had with them and the style of the letters received? UNIDENTIFIED SPEAKER: Impersonal.
- J JNIDENTIFIED SPEAKEK: Imperson
- 4 MR GARY MCKELVEY: Mm.
- 5 MR PETER FRITH: Very coldly, so ...
- MS RACHAEL TERSTEEG: And each of the four rejections there was the same couple of paragraphs at the end of
- the letter each time. I think it was just a standard
- 9 letter that had -- they'd popped a little bit of
- 0 information in beforehand and then that was it and off
- 11 into the post.
- 12 MS FRASER BUTLIN: What effect did that have on you?
- 3 We've talked about the effect of the rejection but if
- you can separate it out, what was the effect of thosecold impersonal communications with standard formletters?
- 17 MS RUBY GILKES: In Anne's case, I mean, I visited
- 8 a hospital just on three occasions, Monday, Tuesday,
- Wednesday, before I went back to London, but I find
- 0 that, you know, she was complaining about certain
- 1 things in the hospital and that she wasn't being
- attended to and she'd keep ring -- because she was in
- a room on her own when I got there, and she said she
- would ring the bell and people wouldn't turn up.
 When I saw the notes, I saw they had, like, the
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- 1 MS FRASER BUTLIN: Just in terms of your interactions with
- Skipton, Ruby, when you were communicating with them,
- how did you find your communications with the Skipton
- 4 Fund?
 - MS RUBY GILKES: Well, it was very vague, very vague, and I would have expected the Skipton Fund, seeing as it
 - is in NHS and the hospital NHS, would collaborate
 - together and say, "Well, Mrs Gilkes said that -- what
- about the death of her sister and, you know, could you
- 10 look into it?" But nothing was done.

1 MS FRASER BUTLIN: I think we are hearing from all the

- 2 panel that problem of the joined up or lack of joined
- up thinking between the Skipton Fund and the NHS in
- 14 terms of records.
- 5 MS RUBY GILKES: I was amazed because the hospital
- 6 consultant had already written to Skipton Fund
- 7 regarding the same thing, hepatitis C. It was all
- 8 there but they did nothing. I don't know.

19 **MR PETER FRITH:** I don't understand why the Skipton Fund 20 didn't believe what professionals were telling them.

- 1 I expect, as a professional, people to understand me
- and believe me. Like you, as a barrister, your
- and believe me. Line you, as a barns advice, I believe you.
- 24 **MS FRASER BUTLIN**: By that you are meaning your treating 25 clinicians were saying, "This was

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1	transfusion-acquired"?	1	experience of going round in circles.
2	MR PETER FRITH: Yes. And they have examined me, they	2	MR GARY MCKELVEY: Yes, I'm just nodding as Andy's
3	have taken looked at my history, "Yes, this is	3	speaking because I agree totally, because you don't
4	definitely transfusion-related". Why wasn't that	4	know where you are going and I have just got two
5	believed? Why did it have to go through all the hoops	5	documents in front of me, so one from the Northern
6	of having to provide the evidence. You know, it is	6	Health and Social Care Trust, the other from the
7	almost calling these clinicians liars.	7	Belfast Health and Social Care Trust. In terms of how
8	MR ANDREW BRAGG: One thing I never understood was that,	8	they make you feel, so it ends in both cases with:
9	why was it my responsibility to interact with the NHS	9	"If you require any further help please do not
10	to get my medical records? Why was it not that when	10	hesitate to contact me."
11	I made an application to the Skipton Fund that they	11	In other words, don't bother because, you know,
12	then facilitated, using the systems that they would	12	they can't if I go back then they send me somewhere
13	know very well, to do that on my behalf and to help	13	else, yeah? So they are closing the door with that
14	them? So I was always conscious that perhaps I'm not	14	last sentence effectively.
15	writing to the right people or I've missed people,	15	MS FRASER BUTLIN: Along those lines, a number of you have
16	because I'm not aware of who I had to approach.	16	had to try to obtain patient records from a multitude
17	I went to the people I thought I needed to do but	17	of hospitals and GP surgeries and the complexities of
18 19	there were probably more that I missed. So, for me, it would have been far more effective if that, once	18 19	a different GP where someone has died.
20	you made application to the Skipton Fund that they	20	Do you have any thoughts on how much the fact that records are dispersed have added to the difficulties?
20	then coordinated the search for medical records. That	20	
22	would be a very relatively simply move that would	22	MR ANDREW BRAGG: Absolutely. It seemed to me absurd that wherever you get treated, so if you move around the
22	make sure the most effective sweep of the medical	23	country, or even in my case I was visiting my
24	records were made available.	24	father and I got sepsis, so in Chesterfield Hospital
25	MS FRASER BUTLIN: Gary, I think you had the same	25	they have medical records for me for that period I was
20	109	20	110
1	in that hospital. They were never passed on to my GP.	1	we not be given the option to actually receive them
1 2	in that hospital. They were never passed on to my GP. In some way you have to bring all this together. You	1 2	we not be given the option to actually receive them ourselves and look after them ourselves? I understand
2	In some way you have to bring all this together. You	2	ourselves and look after them ourselves? I understand
	In some way you have to bring all this together. You have to integrate it. They are my medical records, my	2 3	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been
2 3	In some way you have to bring all this together. You have to integrate it. They are my medical records, my medical history, and yet the system does not look to	2	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been masses of paperwork and masses of records. Surely
2 3 4	In some way you have to bring all this together. You have to integrate it. They are my medical records, my	2 3 4	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been masses of paperwork and masses of records. Surely before an option is taken to destroy, they should try
2 3 4 5	In some way you have to bring all this together. You have to integrate it. They are my medical records, my medical history, and yet the system does not look to integrate it to bring it all into one place.	2 3 4 5	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been masses of paperwork and masses of records. Surely before an option is taken to destroy, they should try to locate that person and say, "Do you want these
2 3 4 5 6	In some way you have to bring all this together. You have to integrate it. They are my medical records, my medical history, and yet the system does not look to integrate it to bring it all into one place. So it isn't standardised, it isn't ordered, and it is not brought together, no wonder you fail.	2 3 4 5 6	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been masses of paperwork and masses of records. Surely before an option is taken to destroy, they should try
2 3 4 5 6 7	In some way you have to bring all this together. You have to integrate it. They are my medical records, my medical history, and yet the system does not look to integrate it to bring it all into one place. So it isn't standardised, it isn't ordered, and it is not brought together, no wonder you fail. MR ROBERT BAMFORTH: It all should be we've got an	2 3 4 5 6 7	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been masses of paperwork and masses of records. Surely before an option is taken to destroy, they should try to locate that person and say, "Do you want these we'll pass these over to you or your current GP",
2 3 4 5 6 7 8	In some way you have to bring all this together. You have to integrate it. They are my medical records, my medical history, and yet the system does not look to integrate it to bring it all into one place. So it isn't standardised, it isn't ordered, and it is not brought together, no wonder you fail.	2 3 4 5 6 7 8	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been masses of paperwork and masses of records. Surely before an option is taken to destroy, they should try to locate that person and say, "Do you want these we'll pass these over to you or your current GP", rather than just blanketly destroy I know it's
2 3 5 6 7 8 9	In some way you have to bring all this together. You have to integrate it. They are my medical records, my medical history, and yet the system does not look to integrate it to bring it all into one place. So it isn't standardised, it isn't ordered, and it is not brought together, no wonder you fail. MR ROBERT BAMFORTH: It all should be we've got an NHS number, so when we have a vaccine for the thing,	2 3 4 5 6 7 8 9	ourselves and look after them ourselves? I understand prior to digitalisation digitisation there had been masses of paperwork and masses of records. Surely before an option is taken to destroy, they should try to locate that person and say, "Do you want these we'll pass these over to you or your current GP", rather than just blanketly destroy I know it's probably not but they would have they don't
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1	because I was quite badly hurt and it's quite	1	would have been and again retrospectively it
2	interesting to get the x-rays out and show them.	2	would have been useful for my mother at the time to
3	MR ANDREW BRAGG: Oh, I wish I'd done that. When I came	3	have had some sort of, I don't know, psychological or
4	back from Norway I came back with a folder this size	4	counselling support, and some guidance maybe as to
5	(indicated). Not only did it have all my medical	5	whether there are any remedies or routes for her to
6	records, I had every x-ray that had been taken while	6	get some level of assistance because suddenly she is
7	I was in the hospital. I made the mistake of taking	7	left on her own. I have two brothers but none of us
8	that with me when I went to Broadgreen Hospital for	8	live at home so she is a little bit isolated. It
9	the first time, and I never saw it again.	9	would have been very useful to have something , but we
10	MS FRASER BUTLIN: For those of you who have been bereaved	10	had nothing. No support.
11	and speaking about loved ones who have died, I have	11	Just one comment regarding the records, in the
12	been asked to ask what your thoughts are on the	12	record recording process, I thought actually it was
13	support that should have been available to you from	13	only after death that they destroyed records but, as
14	the funds in the particular context of applying in	14	I have listened, it appears that you don't have to
15	relation to someone who had died?	15	have died. They can still lose the records or destroy
16	MS RACHAEL TERSTEEG: I don't think the Skipton Fund even	16	them. It is just an observation.
17	know that my husband passed away. Perhaps if	17	MR PETER FRITH: In line with hospital policy.
18	something had been in place whereby there was, as you	18	MR ROBERT BAMFORTH: I think they lose the records they
19	said, more communication between the applicants and	19	want to lose.
20	the Skipton Fund, they would perhaps have some	20	MS FRASER BUTLIN: Sir, do you have any questions you want
21	counselling in place to offer bereaved partners,	21	to ask the panel in terms of themes before we invite
22	parents. That would probably have been really	22	Mr BD to give evidence?
23	helpful.	23	SIR BRIAN LANGSTAFF: No. I don't think I do. I have
24	MS FRASER BUTLIN: Gary, do you have any thoughts on that?	24	listened very carefully to what you have all been
25	MR GARY MCKELVEY: Again, it is a long time ago but it	25	saying.
	113		114
1	MS FRASER BUTLIN: Can I just check with the legal	1	through his own evidence and then ask him to reflect
2	representative?	2	on some of the discussions we have had this afternoon
2 3	representative? In which case, sir, I wonder if we might take	2 3	on some of the discussions we have had this afternoon and he has been listening to those. So hopefully we
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1	not following through on it.	1	to say?
2	But absolutely crucial that we have this, and I'm	2	MS RUBY GILKES: I just want to say thank you very much
3	more than happy to have been involved.	3	for listening and, sir, very much for the work that he
4	SIR BRIAN LANGSTAFF: Thank you.	4	is doing, and what I would like to really see happen
5	MS FRASER BUTLIN: Gary?	5	in my sister's situation at the moment is with the
6	MR GARY MCKELVEY: Right, from a personal point of view	6	document of the death certificate, which has not been
7	I wasn't looking forward to coming here today, so that	7	correctly done, I have family at the moment that we
8	is the first thing. However, I would like really to	8	cannot say what Anne has died of.
9	thank all of the people involved in the Infected Blood	9	I don't know what else to do. I went everywhere,
10	Inquiry team because right from the beginning and	10	lawyers, everybody. I don't know what else to do, and
11	I met a lady this morning because I was trying to sort	11	I would just like that cleared up because my family is
12	of set the history for this when I was sat last night	12	not happy not knowing, not seeing what happened during
13	on my own and she was the first person to contact me,	13	the death of my sister, and I am the one that is being
14	almost four years ago. And those people who visited	14	crushed because I had the power of attorney and they
15	me at home and provided information and support, you	15	say I did not use it correctly as even to let them
16	know, I would like to thank them also. And all of the	16	see the body, even despite. And I don't know really
17	people here on this panel, it has been really quite	17	what to do. I don't know who to go to. There is
18	cathartic to listen to the experience of others	18	nobody out there. Everyone I go to, everywhere is
19	, because I think, as Andy said, sometimes you feel	19	just like it is dead. I don't know.
20	isolated, a little bit remote from what's happening,	20	But with the Skipton Fund up to now, they ask me
21	and the one thing above and beyond anything else is	21	to say that I should go to this advice bureau, which
22	you don't feel believed. And that's all we want, or	22	in my area there is none, and there is nobody to go to
23	I want and hope for the rest, is to be believed.	23	and that I should take it to court, which I'm trying
24	Nothing more. Thank you.	24	now to get a solicitor or a lawyer or whatever to take
25	MS FRASER BUTLIN: Ruby, is there anything you would like	25	the matter to court to get this death certificate
	117		118
1	signed and this hospital that is shut down, they	1	without her I wouldn't be here.
2	completely shut down. They tell me they don't have	2	MS FRASER BUTLIN: Rachael, is there anything you would
2 3	completely shut down. They tell me they don't have nothing else to say. So I don't know really what to	2 3	MS FRASER BUTLIN: Rachael, is there anything you would like to say?
2 3 4	completely shut down. They tell me they don't have nothing else to say. So I don't know really what to do. So I'm in a limbo with family and with the	2 3 4	MS FRASER BUTLIN: Rachael, is there anything you would like to say?MS RACHAEL TERSTEEG: Well, I managed half an hour's sleep
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1	You have all been really good because I have not got	1
2	a lot of faith in this sort of thing. It's never done	2
3	me any good before. And you have all been so helpful	3
4	and everyone I spoke to has been just so helpful,	4
5	put me at ease and sorted out things I can't do	5
6	myself. And it is good to be able to because	6
7	I have kept it to myself for years, to be able to tell	7
8 9	people and I can actually tell people out in the	8 9
9 10	street now about it, where I have never told anyone about it because you have made it, like, official, if	9 10
11	you get what I mean. It's not our fault and so,	10
12	yeah, it's been good to be able to come out with it	12
13	all. And to hear these other people with exactly the	13
14	same stories.	14
15	MS FRASER BUTLIN: Andrew?	15
16	MR ANDREW BRAGG: One final observation and it is about	16
17	regulations.	17
18	The Piper Alpha disaster lost 173 people and the	18
19	Cullen Report fundamentally changed my industry, oil	19
20	and gas and chemical. I hope this Inquiry can do the	20
21	same thing because what I see is fundamental failings	21
22	right across the NHS, not just in terms of how	22
23	specifically it dealt with this but, by implication,	23
24	how it, as an organisation, functions. And I hope	24
25	that that regulatory framework that applies to the	25
	121	
1	most of you, how challenging it was to bring	1
2	yourselves to come to give evidence in this Inquiry,	2
3	and indeed that's underwritten by the fact that the	3
4	next witness will be anonymous and wishes to be	4
5	anonymous and you have chosen not to be. Can I,	5
6	without in any way taking away from him and his	6
7	anonymity, which is fully understandable, applaud your	7
8	courage in being prepared to come at all and being	8
9	prepared to sit here in front of everyone and to tell	9
10	your story to what is out there, the world. It has	10
11	been affirming.	11
12	Can I also say that one of the themes that I have	12
13	picked up, rightly or wrongly, and people can argue	13
14	about that later on in the Inquiry, is that there is	14
15 16	quite a contrast between the evidence that I heard	15 16
17	when we looked at Skipton you will remember the evidence of Mr Fish and others which emphasised,	17
18	I think implied, a lack of appropriate or sufficient	18
19	resource to do what you have all suggested, to look at	19
20	the records, obtain them for people, help them to do	20
21	that because of the challenges of time and money.	21
22	What you have each I think given us is the patient	22
23	perspective.	23
24	It is all very well to look at institutions and	24
25	say, "Well, we can't do that because it will cost too	25
	123	

chemical industry, something similar could actually help shape the NHS to behave differently, because at the moment it seems to me that they are a law unto themselves. And that will not just, you know, reflect on how it's dealt with on HCV but it reflects on a number of other ways in which other unfortunate incidents have occurred. So I would hope that that regulatory approach can form part of the report, about how we can get the NHS as an organisation to shape up and respond effectively. Because it has failed to do so here. Fundamentally, for me, as an organisation, first is do no harm and yet they have done harm to a large number of people in this. And a lot more people than 173 people have died. So the magnitude of the issue, the error, the problem, is far greater in respect of this Inquiry than it was to what happened in my industry. SIR BRIAN LANGSTAFF: Can I for my part thank -- may I apologise first for not thanking you individually. It would be invidious to do so because you are here as a panel but can I thank you all and pick up some of the themes that you have mentioned, particularly in the last few comments. You have said, most of you, not all of you but 122 much and because it will do this and do that", this is what you have been saying to me I think, and I have to decide how right or wrong that is. What you have said is, "What about us? Look at the way we look at it, look at the way we feel", and you have all told me about how you have felt being disbelieved when really what was the basis for that, is I think what you have been asking. So thank you very much for putting that different perspective to us and through this Inquiry to others. You deserve our appreciation and I'm very glad to give it. Thank you. We will take a break then for half an hour. You are very welcome to stay or go. Your life is your own entirely but you are welcome to stay should you wish. We will take a break until shall we say 3.20 pm. MS FRASER BUTLIN: Thank you, sir. SIR BRIAN LANGSTAFF: 3.20 pm. (2.49 pm) (A short break) (3.23 pm) SIR BRIAN LANGSTAFF: Now Mr BD.

- 23 MR BD: Good afternoon.
- 24 SIR BRIAN LANGSTAFF: You are on screen to me and to
- 25 counsel. You are not on screen to anyone else in this

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1 room. I have told people this morning, you may have MR BD: So there was significant bleeding to the point, 1 2 2 heard, I don't know, that there is an anonymity order well, my father found me in the next door neighbour's 3 3 which covers you and your evidence, and I am sure that front yard with blood spurting out of my arm and spent 4 those here don't want to hear me repeat it again, just 4 a lot of the next day cleaning the blood off their 5 5 path. So that's, you know, my memories of the blood to remind you of it. 6 Now, I will ask you to take the oath. You are 6 loss. 7 affirming, so would you repeat after me please. 7 MS FRASER BUTLIN: You underwent surgery at Scarborough 8 MR BD (affirmed) 8 General Hospital in September 1975. 9 Examined by MS FRASER BUTLIN 9 Do you have any recollection of having a blood 10 10 SIR BRIAN LANGSTAFF: Thank you, Ms Fraser Butlin. transfusion? MS FRASER BUTLIN: Mr BD, can you see and hear me? 11 11 MR BD: I don't, no. 12 MR BD: I can, yes. 12 MS FRASER BUTLIN: It is right, isn't it, that your father 13 MS FRASER BUTLIN: When you were 8, you had an accident. 13 has died and your mother is very elderly and doesn't 14 14 know you are infected with hepatitis C? Can you tell us what happened? 15 MR BD: So I was playing in the front driveway of our 15 MR BD: That's right, yes. So my memory of the injury is 16 house and was climbing on the walls and slipped and 16 of seeing the bone sticking out of my arm in hospital, 17 fell, and as I fell it turned out some of the chunks 17 seeing it bleeding excessively, and then being put 18 of brick on the top of the wall were loose and 18 under and taken into surgery. 19 19 MS FRASER BUTLIN: And after surgery, how well were you I pulled them down on top of my arm and broke my arm. 20 MS FRASER BUTLIN: And what was the nature of the break to 20 post-surgery? 21 21 MR BD: So I was in surgery for a number of hours that your arm? 22 MR BD: So I suffered a double compound fracture of both 22 night and then allowed home that night, on condition 23 23 that they brought me back to fracture clinic the next radius and ulna. 24 MS FRASER BUTLIN: How much blood was involved in the 24 morning so they could check the alignment of the 25 accident? 25 bones. By which point there had been significant 125 126 1 further bleeding, which had soaked through the plaster 1 she would not normally be part of the work-up for 2 2 cast, but they decided not to replace it at the time a vitiligo autoimmune raft of tests, but she did it 3 3 because it was too unstable. and it came back positive for hep C. 4 Afterwards, I remember being laid up for some time 4 MS FRASER BUTLIN: You simply said in your statement that 5 5 and feeling pretty awful, but I think that is to be she simply said, "Let's do the lot". 6 expected of an eight-year old having suffered that 6 MR BD: Absolutely. I have spoken to her since, like 7 7 I say, and she's not sure what made her do it, but trauma. 8 MS FRASER BUTLIN: You also remember getting some flu-like 8 thankfully she did. 9 9 symptoms not long after surgery; is that right? MS FRASER BUTLIN: You had a follow-up appointment soon MR BD: Yes, it is, yes. Again, I couldn't attest to 10 after and also a FibroScan after diagnosis. What was 10 11 whether that was just -- I was probably on some fairly 11 the state of your liver when you had that FibroScan? 12 hefty painkillers. MR BD: Bad. Full on cirrhotic. So my liver function 12 13 MS FRASER BUTLIN: How did you come to find you had 13 tests at that point were wildly deranged. And I had hepatitis C? 14 MRI, CT, I had full radiological skeletal survey and, 14 15 MR BD: So completely incidental findings. So I was 15 as you say, FibroScan. The FibroScan came back with 16 actually being investigated for a diagnosis of 16 a -- I can't remember the exact KPA figure but it was 17 17 around 20, which is -- anything over 10 is deemed vitiligo in 2013, which I realised I had, and went to 18 the hospital to get that diagnosis confirmed, and part 18 cirrhotic. MS FRASER BUTLIN: What was your understanding of the 19 of the work up of that was to look at potential 19 20 20 seriousness of cirrhotic liver disease? What were you auto-immune causes of the vitiligo, so they confirmed 21 the diagnosis and did a raft of blood tests. And at 21 told about how serious things were? 22 the point, the SPR carrying out the blood tests 22 MR BD: So I have some medical knowledge, so I knew 23 decided to do hepatitis. 23 immediately it was a death sentence, incurable, 24 24 Now, she's -- I have spoken to her since and she irreversible. So my immediate response was, "Tell me 25 still doesn't really know why she did it. She said 25 how long I've got". 127 128

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4	MC EDACED DUTUNE And what were you told?	4	on the horizon on the users making their way through
1	MS FRASER BUTLIN: And what were you told?	1	on the horizon, so they were making their way through
2 3	MR BD: I was told 10 to 15 years, and that's nine years	2 3	NICE approval. So the decision was made that it was better for me to hang on and hopefully be able to be
4	ago. MS FRASER BUTLIN: Can you tell us anything of the impact	4	treated with one of the new directly acting drugs.
4 5	that had on you, of that news?	4 5	MS FRASER BUTLIN: In 2015 you became aware that the
6	MR BD: Completely devastating. You go from worrying	6	European Medicines Agency had licensed Harvoni.
7	about have I got vitiligo and the vanity around how	7	MR BD: Yes.
8	that might affect your appearance to suddenly that	8	MS FRASER BUTLIN: What did you then do in relation to
9	being so far from relevant it is unbelievable and your	9	that?
10	whole world is turned upside down and suddenly	10	MR BD: So, again, I have lots of close contact with my
11	I was 46 at the time you are told when you are	11	medical team, trying to track the NICE pathway to see
12	going to die. So it was pretty devastating.	12	how long it was going to be until it was available on
13	MS FRASER BUTLIN: You were at that stage unable to have	13	the NHS, and then juggled with the idea of self
14	interferon. Why was that?	14	funding, which was going to cost about 60,000. Each
15	MR BD: So I was profoundly thrombocytopenic, and still	15	time I came to the conclusion that I wanted to self
16	am.	16	fund because I was fully aware that all the time I was
17	MS FRASER BUTLIN: That is a low platelet count?	17	still HCV positive it was causing further damage to my
18	MR BD: Yes. And neutropenic, low neutrophils,	18	liver. I the NICE approval looked like it was only
19	lymphopenic, low lymphocytes, and so the feeling was	19	two months away each time, and so although knowing
20	that interferon would be it could probably be	20	that NICE approvals constantly get kicked down the
21	supported through haematology but it would be risky	21	road then I still kept for a while thinking, no, I'm
22	because it is likely to drop my counts even further.	22	not going to self fund, then eventually made the
23	It would take an awful lot of support without	23	decision I was going to self fund, and then a week
24	a guarantee that it would clear the virus, and also,	24	later NICE approved it.
25	at this point, the new directly acting antivirals were	25	MS FRASER BUTLIN: You had arranged to borrow the money in
	129		130
1	June 2015.	1	MS FRASER BUTLIN: You cleared the virus but continued to
1 2	June 2015. MR BD: Yes, I had.	1 2	MS FRASER BUTLIN: You cleared the virus but continued to have six-monthly FibroScans.
2	MR BD: Yes, I had.	2	have six-monthly FibroScans.
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(33) Pages 129 - 132

1	of me is also debating internally whether I should do	1	SKIP0000072_006. And it is page 5 I would like,
2	it because I'm trying to make sure that my partner	2	please, Lawrence.
3	will be financially secure when I'm gone. It affects	3	What we can see here on the left is:
4	every decision.	4	"Compound [fracture] lower [left] end radius and
5	MS FRASER BUTLIN: In terms of the Skipton Fund, in	5	ulna."
6	March 2014, you were told about the fund by your	6	Then on the right:
7	treating doctor, is that right?	7	"Compound [fracture] of [left] radius and ulna."
8	MR BD: Yes.	8	Something that's difficult to read and then
9	MS FRASER BUTLIN: And at that point you tried to obtain	9	a little further down there is a note that Pethidine
10	your records from Scarborough Hospital?	10	had been given. Then:
11	MR BD: Yes.	11	"However on call contacted for advice. Sutures to
12	MS FRASER BUTLIN: What were you told by them? What were	12	the closure to the wound. No vascular or tendon
13	you told had happened to your records?	13	injury. Check x-ray in the morning."
14	MR BD: That they had been destroyed. So that everyone's	14	That's what's on the A&E record. And that's the
15	records were destroyed upon or shortly after their	15	only document that you were able to obtain in relation
16	25th birthday.	16	to the entire incident, is that right?
17	MS FRASER BUTLIN: Were you required you were provided	17	MR BD: It is, yes.
18	with at least one page from Scarborough Hospital in	18	MS FRASER BUTLIN: When you applied to the Skipton Fund
19	terms of the accident and emergency department and we	19	the first time, you were rejected by them?
20	are going to look at that document in a moment. When	20	MR BD: That's right.
21	they sent you that, were you required to pay for the	21	MS FRASER BUTLIN: You then re-applied to the EIBSS in
22	limited records they were able to provide you with?	22	2020, is that right?
23	MR BD: No, I wasn't.	23	MR BD: Yeah.
24	MS FRASER BUTLIN: Could we just turn to the document	24	MS FRASER BUTLIN: And if we can turn to that document.
25	which is the A&E record.	25	WITN4211002, please. It is page 3 I would like to
	133		134
1	start with	1	this means that both bones were fractured, and the
1	start with. We can see here that your application has been	1	this means that both bones were fractured, and the fractures were in the middle of my forearm. Further
2	We can see here that your application has been	2	fractures were in the middle of my forearm. Further,
2 3	We can see here that your application has been declined. If we go down the page it says this:	2 3	fractures were in the middle of my forearm. Further, just to clarify, the word 'compound' means that this
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1	then subsequently justify a rejection of the appeal.	1	couldn't provide because their records had been
2	And either way I don't think that is a panel that's	2	destroyed. So I wasn't so much devastated by the
3	fit for purpose. And I was very angry.	3	rejection, I was angered by the manner of the
4	MS FRASER BUTLIN: And your appeal was rejected again.	4	rejection. It felt patronising and disrespectful to
5	MR BD: Yes. And it was rejected again without any	5	my injury. I would have hoped that they would at
6	reference whatsoever to my description of you know,	6	least try to understand what had happened and
7	or highlighting of them describing my injury as	7	understand the full extent of the injury and then make
8	a broken wrist.	8	an educated professional assessment of that.
9	Now, I would at the very least have expected them	9	Perhaps with, you know, recourse to appropriate
10	to say, "Yes, you're right. It doesn't say 'wrist'.	10	professionals you know, they say in their letter
11	Sorry about that. It says you had a broken radius and	11	that on their panel they have got a liver expert,
12	ulna", but there was no acknowledgement of it	12	a haematology expert. Now, my injury was orthopaedic.
13	whatsoever.	13	So to reject on the basis that I would hope that
14	MS FRASER BUTLIN: I think you were listening into the	14	a panel like this, to function properly, would perhaps
15	earlier discussion with the panel this afternoon, and	15	canvass the opinion of one or two paediatric
16	one of the things we talked about was the effect of	16	orthopaedic surgeons, preferably ones who had
17	the rejections on people's mental wellbeing. Can	17	experience of treatment protocols in the '70s and say
18	you do you have any reflections on that for	18	to them, "Do you think a transfusion is likely in that
19	yourself?	19	circumstance, now we have all the details of that
20	MR BD: Yes. I mean, I think the main responses I heard	20	injury?" And there is very little effort made, in my
21	earlier were both anger and devastation.	21	opinion.
22	Now, I think mine was mainly anger because I was	22	MS FRASER BUTLIN: That was something that the panel also
23	fully expecting to be rejected, because I was aware	23	discussed earlier this afternoon, of the question of
24	anecdotally that the Skipton Fund appeared to be set	24	the Skipton Fund being more proactive in terms of
25	up to require a level of proof that most people	25	obtaining information and obtaining records. Do you
	137		138
1	have any reflections on that part of our discussion?	1	that all my records had been destroyed because I don't
1 2	have any reflections on that part of our discussion? MR BD: So, yes, I agree with what they said entirely. In	1 2	that all my records had been destroyed because I don't know whether I was just naive, but I wasn't aware of
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1	bad. But one of the panel did make the point earlier	1	l disputed them calling my break a broken wrist.
2	on that in a lot of industries their record keeping	2	I could send them a photograph of the scar. It is in
3	has to be pristine.	3	the middle of my forearm, it is not my wrist, so they
4	The NHS seems to be able to get away with writing	4	could have done that, and they could have asked for my
5	very perfunctory notes in a completely illegible way	5	testimony. And I think, and a number of the panel
6	and only half-filled-in records and half-retained	6	earlier on made the same point, that the testimony of
7	records, which is pretty awful.	7	the people themselves, us, is ignored. It is almost
8	Now, it has all happened and we can't change that	8	that that is taken as, "Let's not believe that". We
9	now. One of the lessons that has to come out of	9	were there. I was there. I know and I still carry
10	an inquiry like this has to be that they have got to	10	the scars so I know what the injury was better than
11	get better.	11	anybody. Better than anybody alive, actually, because
12	MS FRASER BUTLIN: Given the state of the records	12	my father is the only other person who saw that
13	historically, do you have any reflections on how the	13	injury, because my mum never looked at it, so I saw it
14	Skipton Fund should have been operating within that	14	and he saw it.
15	context?	15	Now, they didn't even ask me any of those
16	MR BD: So the constant reference through the Skipton Fund	16	questions. It is almost like this is why I used
17	and the EIBSS to "There is sufficient evidence" is	17	the word "patronising" earlier on. It treats us like
18	really irksome when that evidence has been destroyed	18	they know best. It's almost like getting a pat on the
19	You know, don't keep telling me there is no	19	head, "No, you just had a broken wrist". Well,
20	evidence. I know there is no evidence. Don't then	20	actually no, I didn't just have a broken wrist.
21	use that for a reason for rejecting it. We need to	21	MS FRASER BUTLIN: Having listened to the panel earlier,
22	take it as read that there is no evidence because it	22	do you have any other reflections on what was
23	has been destroyed. Now, we need to look at the	23	discussed?
24	injury and we need to look at it with due diligence.	24	MR BD: I don't. I mean, I think the main points I wanted
25	You know, they should have come back to me when	25	to make through this were that it is not the
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1	rejection. You know, when there isn't the evidence	1	them, and they'd come back and said, "No, you wouldn't
2	I don't know for a fact that I had a blood	2	have had a transfusion", I would have said, "Okay,
3	transfusion. Nobody knows that. And so there has to	3	maybe I didn't", and I would have felt like it had
4	be a tolerance set somewhere or else anybody could	4	been taken seriously, thoroughly examined and reached
5	write in and say, "Give me compensation, I have HCV".	5	a logical, professional conclusion.
6	There has to be a tolerance set somewhere. But in	6	That's what I would have expected from a fit for
7	light of the fact that everybody's data has been	7	purpose support scheme.
8	destroyed, everybody's records have been destroyed,	8	MS FRASER BUTLIN: Thank you.
9	that tolerance doesn't seem to be and whether this	9	Sir, do you have any questions for Mr BD?
10	is down to what Sir Brian said earlier on about	10	SIR BRIAN LANGSTAFF: No, I don't think I do.
11	Skipton's claim to lack of funding, whether it is down	11	MS FRASER BUTLIN: Mr BD, is there anything else you would
12	to lack of funding or whatever, it doesn't feel to me	12	like to add in relation to your evidence?
13	like there is due diligence around the process.	13	MR BD: No, there isn't. I just want to thank you for the
14	There's been no effort made to fully understand the	14	opportunity to tell my story and it has been very
15	injuries or the conditions that some of the other	15	interesting and illuminating listening to the rest of
16	panel described earlier on.	16	the panel as well.
17	I mean, I was quite frankly shocked by the level	17	SIR BRIAN LANGSTAFF: Can I, for my part, thank you very
18	of evidence that some of the panel earlier today had,	18	much for having made the courage to come and tell us
19	way in excess of mine, and they still got rejected.	19	what has been powerful and I think still angry
20	I was listening to them thinking, well, how on earth	20	testimony and you are agreeing with that I can see.
21	can they be rejected? It is obvious that they had	21	MR BD: Yes. The EIBSS rejection is quite recent so
22	transfusions within that time frame. And I would	22	that's probably why I'm still if I talk about it
23	have if they had explored the injury, taken my	23	l get passionate, shall I say.
24	testimony about the severity of the injury, spoken to	24	SIR BRIAN LANGSTAFF: Yes, I have a feeling it is quite
25	paediatric orthopaedic surgeons and got testimony from	25	raw still.
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The Infected Blood Inquiry

1	MR BD: Yes.	1	INDEX
2	SIR BRIAN LANGSTAFF: Well, thank you very much anyway for	2	MR ANDREW JAMES BRAGG (sworn)
3	telling us. You have covered not only the question of	3	MR GARY HUGH MCKELVEY (affirmed)
4	rejection but also the recent knowledge of it and the	4	MS RUBY PERLINE GILKES (affirmed)
5	recent treatment, so thank you.	5	MR PETER FRITH (affirmed)
6	MR BD: Pleasure.	6	MS RACHAEL JOY TERSTEEG (sworn)
7	SIR BRIAN LANGSTAFF: Now, Ms Fraser Butlin, tomorrow?	7	MR ROBERT NORMAN BAMFORTH (sworn)
8	MS FRASER BUTLIN: Tomorrow, sir, we will hear from	8	Examined by MS FRASER BUTLIN
9	a panel of witnesses about the experiences of people	9	MR BD (affirmed)
10	with hepatitis C who cleared the infection without	10	Examined by MS FRASER BUTLIN
11	treatment.	11	
12	The people who are giving evidence are	12	
13	Wayne Gathercole, Marlene Neve, Kevin Roberts and	13	
14	Steven Towsey.	14	
15	SIR BRIAN LANGSTAFF: Very well. Tomorrow at 10.00.	15	
16	(3.54 pm)	16	
17	(The Inquiry adjourned until 10.00 am on Tuesday,	17	
18	27 September 2022)	18	
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	MS RUBY PERLINE GILKES (affirmed)	2
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	MS RACHAEL JOY TERSTEEG (sworn)	3
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