

Friday, 30 September 2022

(10.00 am)

SIR BRIAN LANGSTAFF: Welcome, all. Let me just say a word or two first to everyone who is here. It has been quite some time since I last reminded those who are here to be very careful in taking photographs around this building, because it may inadvertently identify someone who does not wish their picture to be out there. They may not be anonymous but nonetheless they are entitled to their privacy, so please be respectful, as you have been in the past, and I hope you don't mind my reminding you. You will wonder about the reason why Regina Cheptaniu sits closer to me than she does to Ms Fraser Butlin, and it is for reasons such as that.

Now, in a moment or two Mary will invite you to take the oaths and then Ms Sarah Fraser Butlin will ask you the questions.

Mary.

MS REGINA ALICE CHEPTANIU (sworn)

MR WAQAR BASHIR AHMAD (sworn)

MS GHUFRANA QURESHI (sworn)

Questioned by MS FRASER BUTLIN

MS FRASER BUTLIN: Regina.

MS REGINA CHEPTANUI: Yes.

1

MS FRASER BUTLIN: Soon after you arrived in the UK you then became pregnant with your daughter.

MS REGINA CHEPTANUI: Yes.

MS FRASER BUTLIN: And you gave birth to her in 1973?

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: And that birth was very different, wasn't it?

MS REGINA CHEPTANUI: It was very difficult in many ways.

I was new in England and I was faced by all white

people -- I'm not trying to say wrong thing -- and

I was scared. Even just to go to clinic, I was

scared. It was new life.

MS FRASER BUTLIN: And during the delivery you lost a lot of blood.

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: And you required and were given a blood transfusion.

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: Could we turn to a document -- it is going to come on the screen, but Regina, you don't need to particularly read it, it is so that Sir Brian can see what we have looked at.

WITN6966002, please.

It relates to a later time. We can see in the

top left corner, it is very faint, "1976". But we

3

MS FRASER BUTLIN: You are a British Kenyan.

MS REGINA CHEPTANUI: Yes, I am.

MS FRASER BUTLIN: And you moved to the UK in 1972 when you were about 25.

MS REGINA CHEPTANUI: Yes.

MS FRASER BUTLIN: You lived in Barbados from 2002 to 2016?

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: But otherwise, since 1972 you have lived in the UK?

MS REGINA CHEPTANUI: Yes.

MS FRASER BUTLIN: You had two of your children when you were in Kenya; is that right?

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: And you did not require a blood transfusion for either of those births?

MS REGINA CHEPTANUI: No, I didn't.

MS FRASER BUTLIN: Can you tell us why you are so clear about that? They were straightforward births at home, I think.

MS REGINA CHEPTANUI: In Kenya, you can request for a midwife to come home, because -- if you don't want to go to hospital. Same thing how they do it here. So my two children were born at home with a qualified midwife.

2

have under that a table dealing with your obstetric history and we can see "1973", the third entry on the table, and then circled we see "Bled - Transfused 2".

MS REGINA CHEPTANUI: Yes.

MS FRASER BUTLIN: And your understanding of this is that -- sorry, the other point we see on the top right, starred, "Transfusion - 2 pints".

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: And that's your understanding that for your third baby, third delivery, you were transfused with two pints of blood.

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: After the arrival of your daughter until 1994 what was your health like?

MS REGINA CHEPTANUI: My health after my daughter was now very bad, because I start having pain, my back pain I start having my body reacting like pain at night, but I put it that problem is a part of the child, and as well I was in pain all the time with my back.

MS FRASER BUTLIN: In 1994 you went to give blood?

MS REGINA CHEPTANUI: Yes, I did.

MS FRASER BUTLIN: Can you tell us what happened after you donated the blood?

MS REGINA CHEPTANUI: Yes. 1994 my manager said to me, "Would you like to give blood? Can you come with me?"

4

1 I said, "Oh, yes, why not? Somebody gave me
2 blood to save my life so I'm going to give blood to o."
3 So I went with her and I donated blood and I was
4 so happy that I done that, to help somebody else. And
5 coming Saturday, the following Saturday, I received
6 a letter saying, "Refuse your blood donation because
7 we find you got jaundice". And I couldn't understand
8 what is jaundice because I never heard of that. So my
9 heart start beating and I'm worried. And because i
10 is Saturday I couldn't go back to ask no question t
11 nobody. So I waited until Monday.
12 **MS FRASER BUTLIN:** And at that point you then went to see
13 a doctor about what this letter meant?
14 **MS REGINA CHEPTANUI:** Yes.
15 **MS FRASER BUTLIN:** What did they tell you?
16 **MS REGINA CHEPTANUI:** I went to the same general hospital,
17 Southampton General Hospital, where I gave blood, and
18 I went and saw a doctor there and I asked him, "Wha
19 is this jaundice?"
20 And he looked at me and he said, "Let me look at
21 your eyes". He said, "Oh, nothing wrong with you."
22 I said to him, "No, you can't say nothing wrong
23 with me while you are saying to me to refuse my blood
24 donation."
25 So I said to him I would like to have another

5

1 **MS FRASER BUTLIN:** Then after about a year no further
2 follow-up happened?
3 **MS REGINA CHEPTANUI:** No.
4 **MS FRASER BUTLIN:** In 2018 you then went to your GP for
5 a medication review.
6 **MS REGINA CHEPTANUI:** Yes.
7 **MS FRASER BUTLIN:** What happened when you met with the GP
8 then?
9 **MS REGINA CHEPTANUI:** That is after when I came back from
10 Barbados I joined a new GP. Very near my house. M
11 flat. When I went there I said to him, "Oh, I'm
12 here", and he said to me, "I am going to ask you about
13 your repeats", and he said to me, "What do you take
14 for hepatitis C?" And I was in denial completely
15 because I was told that I am clear. And how can I be
16 that I got hepatitis C?
17 So he said to me, "Don't worry" -- I said to
18 him, "I haven't got it", and he said to me, "Don't
19 worry, we are going to do tests, we are going to take
20 blood and test you for HIV and hepatitis C."
21 **MS FRASER BUTLIN:** And those tests showed that you were
22 still infected with hepatitis C?
23 **MS REGINA CHEPTANUI:** Yes.
24 **MS FRASER BUTLIN:** You were then referred to
25 a hepatologist.

7

1 test. And he gave me test. He took my blood and test
2 it, but he never said nothing, he said to me, "You are
3 okay".
4 **MS FRASER BUTLIN:** Later on you then received another
5 letter confirming that you had been infected with
6 hepatitis C?
7 **MS REGINA CHEPTANUI:** Yes, I did.
8 **MS FRASER BUTLIN:** And you were asked to go for a biopsy
9 on your liver?
10 **MS REGINA CHEPTANUI:** Yes, I did.
11 **MS FRASER BUTLIN:** So what happened when you attended the
12 appointment at the hospital to discuss that?
13 **MS REGINA CHEPTANUI:** I said to them, "What are you going
14 to do with me, with this biopsy?" Because I wanted to
15 know what it is. And they said they will inject the
16 needle and pinch my liver. I said to them, "No, I'
17 not having my liver pinched, if it is already damaged
18 you will be spreading more viruses on my liver". S
19 I refused to have it.
20 **MS FRASER BUTLIN:** And your recollection is that your GP
21 then did liver function tests for about a year.
22 **MS REGINA CHEPTANUI:** Yes.
23 **MS FRASER BUTLIN:** But then you were told that the liver
24 was fine.
25 **MS REGINA CHEPTANUI:** Yes, I was told the liver is fine.

6

1 **MS REGINA CHEPTANUI:** Yes, I did.
2 **MS FRASER BUTLIN:** When you saw the hepatologist, what
3 were you told then about the condition of your liver?
4 **MS REGINA CHEPTANUI:** First of all they had to take the
5 scan instead of pinching my liver. Then he said to me
6 that my liver is affected with three or four million
7 viruses and I have to have medication for it so
8 that -- to try and clear my virus.
9 **MS FRASER BUTLIN:** What was the impact on your mental
10 well-being of being told that you were still infected
11 with hepatitis C?
12 **MS REGINA CHEPTANUI:** I was annoyed because first of all
13 I was told that -- after having liver function ever
14 other three months, I was told that I'm clear. And
15 when they said to me I'm not clear, I was so annoyed,
16 and especially knowing that I'm still suffering and
17 they said to me I'm clear. I felt that I'm nothing
18 **MS FRASER BUTLIN:** You've said in your statement that
19 finding out that you had hepatitis C made you feel
20 dirty?
21 **MS REGINA CHEPTANUI:** Yes.
22 **MS FRASER BUTLIN:** Even though you know it is not your
23 fault, you still feel really dirty?
24 **MS REGINA CHEPTANUI:** Yes. Yes. Even up to today, I feel
25 that if I tell people I have hepatitis C they will

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1 think I'm dirty, and that is making me to be lonely
 2 And even I worry about -- about it because I don't
 3 talk about it. I try to avoid. But I did tell my
 4 church to pray for me.
 5 **MS FRASER BUTLIN:** And you've said in your statement they
 6 were supportive and have kept you going?
 7 **MS REGINA CHEPTANUI:** Yes.
 8 **MS FRASER BUTLIN:** You underwent treatment for the
 9 hepatitis C. What can you tell us about the side
 10 effects for you?
 11 **MS REGINA CHEPTANUI:** The side effects was very bad,
 12 because this medication was actually made for -- to
 13 suit me, to suit my liver, and I started -- I think it
 14 is called Marvet (sic).
 15 **MS FRASER BUTLIN:** It was Maviret, wasn't it?
 16 **MS REGINA CHEPTANUI:** Yes, Maviret. Yes. I start taking
 17 them and every night I take them my stomach will be
 18 bloated. As well, I have cramps in my feet. Very
 19 uncomfortable. And then I get sick mixed -- like it's
 20 white and -- like mixed blood, like when you mix
 21 strawberry in yoghurt, you see how it will start when
 22 blood was in it.
 23 **MS FRASER BUTLIN:** The medication you were told did clear
 24 the hepatitis C at that point?
 25 **MS REGINA CHEPTANUI:** Yes, it did.

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1 today. It is still there. So I just didn't want to
 2 talk to nobody even -- because doctors, they are not
 3 helping me. If I go there they are not giving me a
 4 good answer back. As one day I went there saying to
 5 them, "My feet are burning", which was burning like
 6 fire. And doctor call me back and he said to me it is
 7 old age. And I was so annoyed to hear him calling me
 8 time for going to -- going home. Because since Covid
 9 you don't see doctor face to face, you got to wait
 10 until they make appointment for you to go and see
 11 them. And he called me about nearly 6.30 and I think
 12 he was going home or he just remember, "Oh, I was
 13 supposed to call Cheptanui but I didn't call her". So
 14 when he called me, he said to me, "Can I help you, it
 15 is Dr so and so, can I help you?" And I said to him,
 16 "Yes, I just want to know what's wrong with me, my
 17 feet are burning and burning like fire. I can even
 18 imagine if I close my eyes it is like fire coming out
 19 of my -- especially left foot". And he said to me,
 20 "Oh, that's old age". And I was so annoyed, I didn't
 21 even want to talk to him again.
 22 So the following morning I rang the surgery and
 23 I spoke to the surgery manager and I said to him, "I'm
 24 not happy for the doctor to say to me what I'm
 25 suffering is because of old age. Doesn't mean that

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1 **MS FRASER BUTLIN:** But what's the situation now in terms
 2 of your health, your physical health?
 3 **MS REGINA CHEPTANUI:** Mentally I'm not happy, the way
 4 I was treated. I did not have nobody talking, telling
 5 me anything or counselling me to tell me what is
 6 this -- hepatitis C is doing to me. So -- and my body
 7 is completely different from the time I came to this
 8 country before I had my daughter. I ache. And even
 9 sometimes I ache there. If I'm lying on a mattress it
 10 will be so painful and I have to sit down and my
 11 sleeping is not good at all. I will sleep probably
 12 two hours in a night because of struggling -- I have
 13 to sit down to turn. I can't turn normal how people
 14 turn in the bed or how I used to turn in bed before
 15 **MS FRASER BUTLIN:** And you have continued to struggle with
 16 your mental wellbeing?
 17 **MS REGINA CHEPTANUI:** Yes.
 18 **MS FRASER BUTLIN:** Do you want to tell us anything about
 19 that?
 20 **MS REGINA CHEPTANUI:** I start worrying and thinking about
 21 is there any life, but I couldn't say that to doctors
 22 because if I say that I know they are going to give me
 23 tranquilisers, because I have been once in
 24 tranquilisers when I was divorcing my husband. And
 25 I never took them but still remain in my record up to

10

1 because you are old you can be left just to suffer"
 2 And I said to him, "I don't want to see him again.
 3 I don't ever want to see him". And it was put in the
 4 record I don't want to see him.
 5 **MS FRASER BUTLIN:** You were advised about the English
 6 Infected Blood Support Scheme and you applied for
 7 financial assistance.
 8 **MS REGINA CHEPTANUI:** Yes, I did.
 9 **MS FRASER BUTLIN:** Your application was rejected.
 10 **MS REGINA CHEPTANUI:** Yes.
 11 **MS FRASER BUTLIN:** What was the reason given for that?
 12 **MS REGINA CHEPTANUI:** The reason, first, when I applied,
 13 Dr -- my doctor was very keen for me to have that
 14 application and then when I filled in, I took it back
 15 to haematologist, Dr Wright, and I filled in but he
 16 never send, because I was expecting him to send it
 17 back to him so that I can post it and read what he
 18 said but he never. He sent it direct to ...
 19 **MS FRASER BUTLIN:** EIBSS.
 20 **MS REGINA CHEPTANUI:** Yes. Then they sent saying that my
 21 application did not succeed. Before that they start
 22 asking me to send them my driving licence, and when
 23 I sent my driving licence they said to me that "What,
 24 you were born in Kenya?" I said, "Yes, I am Kenyan,
 25 but I am a British subject". And he said to me, "Oh,

12

1 you got blood from ... G4".

2 **MS FRASER BUTLIN:** That you had genotype 4?

3 **MS REGINA CHEPTANUI:** Yes, genotype 4. And I said to him,

4 "What is that?" But that genotype 4 is in my record

5 of when I had my test for my daughter when I was --

6 before I went to have her. That is in the record.

7 And I came to know about it because when my record was

8 transferred from my previous doctor to my new doctor,

9 they did transfer the 1973 record to my doctor, to my

10 GP.

11 **MS FRASER BUTLIN:** So the reason given was explained to

12 you then as well by Dr Wright himself.

13 **MS REGINA CHEPTANUI:** Yes.

14 **MS FRASER BUTLIN:** And if we look at that: WITN6966004.

15 If we just pick up five lines from the bottom.

16 He is explaining to you the decision that the EIBSS

17 has made:

18 "I think the crux of it is that the type of

19 virus you have (genotype 4) is most common in Africa

20 and it is quite uncommon in the UK and the assessor

21 will have made a decision on a balance of probability

22 that you are more likely to have acquired the

23 infection outside the UK."

24 The letter from the EIBSS said it had most

25 likely come from a BCG vaccination in Kenya; is that

13

1 in the UK, in the January of '84 --

2 **MR WAQAR AHMAD:** Yes.

3 **MS FRASER BUTLIN:** -- to remove a bladder stone.

4 **MR WAQAR AHMAD:** Yes.

5 **MS FRASER BUTLIN:** Again, as far as you know, you didn't

6 require any blood?

7 **MR WAQAR AHMAD:** No.

8 **MS FRASER BUTLIN:** You were then admitted again in

9 October 1984.

10 **MR WAQAR AHMAD:** Yes.

11 **MS FRASER BUTLIN:** And on this occasion it was a planned

12 elective operation.

13 **MR WAQAR AHMAD:** Yes.

14 **MS FRASER BUTLIN:** Again, to remove another bladder stone?

15 **MR WAQAR AHMAD:** Yes.

16 **MS FRASER BUTLIN:** Before the October 1984 operation,

17 Professor Easthaugh came and saw you.

18 **MR WAQAR AHMAD:** Yes.

19 **MS FRASER BUTLIN:** What did he tell you?

20 **MR WAQAR AHMAD:** He said things were okay, and probably --

21 because they say in one year you having a second

22 operation, you might have to have some blood, you

23 know, for -- in case anything happens. So that was

24 the discussion between me and him.

25 **MS FRASER BUTLIN:** Your understanding is that you were

15

1 right?

2 **MS REGINA CHEPTANUI:** Yeah, that's what they said to me,

3 but it wasn't true. It wasn't true. Because G4 type,

4 genotype 4 blood group, I'm not denying that, but what

5 they are not saying, they are not saying that I had

6 blood transfusion in England in 1973. So they are

7 trying -- they are trying to say to me genotype 4

8 from Kenya. I'm not denying that. Because I had it

9 before even I had my daughter. But they are not

10 trying to say, "You had this blood transfusion in

11 England". So that is something they don't want to

12 acknowledge all the time.

13 **MS FRASER BUTLIN:** Thank you.

14 Waqar, you were born in Pakistan.

15 **MR WAQAR AHMAD:** Yes.

16 **MS FRASER BUTLIN:** And came to the UK as a teenager in the

17 early 1970s; is that right?

18 **MR WAQAR AHMAD:** Yes.

19 **MS FRASER BUTLIN:** You had an operation in Pakistan in

20 your late teens to remove a kidney stone.

21 **MR WAQAR AHMAD:** Yes.

22 **MS FRASER BUTLIN:** But you didn't receive any blood on

23 that occasion?

24 **MR WAQAR AHMAD:** Absolutely not.

25 **MS FRASER BUTLIN:** Then in 1984 you underwent an operation

14

1 given blood during that operation?

2 **MR WAQAR AHMAD:** Absolutely, yes.

3 **MS FRASER BUTLIN:** In 1988 you were told that you needed

4 another operation to remove another bladder stone?

5 **MR WAQAR AHMAD:** Yes.

6 **MS FRASER BUTLIN:** But you were warned that on that

7 occasion you might not be able to have children after

8 that operation?

9 **MR WAQAR AHMAD:** Yes.

10 **MS FRASER BUTLIN:** So you and your wife decided to wait

11 for the operation --

12 **MR WAQAR AHMAD:** Yes.

13 **MS FRASER BUTLIN:** -- until after you had had your two

14 daughters?

15 **MR WAQAR AHMAD:** Yes.

16 **MS FRASER BUTLIN:** So you then had that surgery you think

17 in late 1990 or early 1991.

18 **MR WAQAR AHMAD:** Yes, I did.

19 **MS FRASER BUTLIN:** The operation was a success and you

20 went on to have another daughter and a son?

21 **MR WAQAR AHMAD:** Yes, true.

22 **MS FRASER BUTLIN:** But you don't think you required blood

23 in that operation?

24 **MR WAQAR AHMAD:** No.

25 **MS FRASER BUTLIN:** From about 1994 you have told us in

16

1 your statement that your health began to deteriorate.
 2 **MR WAQAR AHMAD:** Yes.
 3 **MS FRASER BUTLIN:** What can you tell us about that?
 4 **MR WAQAR AHMAD:** Well, I started getting unwell. If we
 5 were in night time and the swollen leg and the swollen
 6 feet most of the time. So, therefore, I didn't know
 7 what was happening and stuff and, you know ... so
 8 I approached to my doctor, because I used to go to see
 9 Professor Easthaugh and Professor Bassendine for my
 10 diabetes. And that's when they told me they are going
 11 to go and do some more investigation. And they did
 12 and they said I have a liver enzyme very high, and
 13 I said "What are they?" I was with my wife. And they
 14 didn't know. They had no answer for that.
 15 But I did suffer quite -- pretty bad until,
 16 I would say -- it was keep going on but there was no
 17 cure, they never said what exactly it is about my
 18 liver. All I have been told by the Freeman Hospital:
 19 you have -- your liver is pretty -- enzyme is high and
 20 your liver is not working as much as it should be
 21 working, and that was in 1995 and it was Dr Lee(?),
 22 Chinese doctor, who sat with me and my wife and
 23 explained.
 24 And not until later on, in 1998 I believe, when
 25 my wife was pregnant with my son and unfortunately

17

1 **MR WAQAR AHMAD:** Yes.
 2 **MS FRASER BUTLIN:** Which seemed to be entirely unrelated
 3 to the stroke?
 4 **MR WAQAR AHMAD:** Yes, they said it's got nothing to do
 5 with the stroke, no.
 6 **MS FRASER BUTLIN:** There was something else going on they
 7 wanted to investigate?
 8 **MR WAQAR AHMAD:** Yes.
 9 **MS FRASER BUTLIN:** So they took some blood tests.
 10 **MR WAQAR AHMAD:** Yes, they did.
 11 **MS FRASER BUTLIN:** Were you told about those results at
 12 that point?
 13 **MR WAQAR AHMAD:** No, they didn't tell me.
 14 **MS FRASER BUTLIN:** Then your wife was with you one day and
 15 tell us what happened?
 16 **MR WAQAR AHMAD:** Yes. One day she came and she sat on the
 17 chair and she was just -- like, looked and there was
 18 a few papers lying on the floor under my bed, and she
 19 picked the papers up and the papers said -- she started
 20 reading it and she said, "Oh, what's this, hepatitis C
 21 positive?" I says, "I don't know". She says, "Oh, it
 22 says here on the paper, it says you are hepatitis C
 23 positive". I says, "Oh, I don't know". So therefore
 24 she called the doctor, a Dr Ruth, and she came in and
 25 she asked Dr Ruth. But Dr Ruth herself didn't know

19

1 I had a massive stroke.
 2 Excuse me.
 3 **MS FRASER BUTLIN:** Take your time.
 4 **MR WAQAR AHMAD:** I just get upset, you know, when I talk
 5 about stuff.
 6 **MS FRASER BUTLIN:** I can read things out of your witness
 7 statement if you prefer, or we can just take some
 8 time.
 9 **MR WAQAR AHMAD:** No, it is okay. It's okay.
 10 So after I had this stroke I was removed from
 11 hospital, Freeman Hospital to Cherryburn.
 12 **MS FRASER BUTLIN:** And that is a rehabilitation unit --
 13 **MR WAQAR AHMAD:** Yes, that's it, for the -- yeah, for
 14 stroke. So I was starting to get very unwell there.
 15 And I asked my doctor, I think it was Dr Ruth, yeah
 16 and she says, "I'll have to do some, you know, test".
 17 So, therefore, they did the test and (unclear) and
 18 I think during that day my wife used to come and see
 19 me.
 20 **MS FRASER BUTLIN:** Just pause there. Let's take a few
 21 steps backwards. When you were at Cherryburn, you
 22 said you were getting very unwell.
 23 **MR WAQAR AHMAD:** Yes.
 24 **MS FRASER BUTLIN:** You were having uncontrollable shivers
 25 and high temperatures; is that right?

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1 much about what's happening, what hepatitis C is. So
 2 I did approach to Freeman Hospital, the specialist,
 3 the liver specialist and therefore they came and
 4 talked to both of us.
 5 **MS FRASER BUTLIN:** What were you advised by the
 6 hepatologist, the liver doctor?
 7 **MR WAQAR AHMAD:** Once they said what hepatitis C is and
 8 what can that do to damage, not only you, to your
 9 family, was the worst thing.
 10 **MS FRASER BUTLIN:** And they advised you to keep things
 11 separate; is that right?
 12 **MR WAQAR AHMAD:** They told me to keep your clothes, your
 13 everything separate from your family, and even one
 14 point they said, you know, if you got a blood --
 15 because I used to have insulin and they say, "if you
 16 see any blood on your clothes, you must take them out
 17 and burn them or throw them away, put them in the
 18 bucket and throw them away". And it was very, very
 19 hard and, you know ... very hard for me. It was very
 20 hard.
 21 **MS FRASER BUTLIN:** At that point you had three young
 22 children.
 23 **MR WAQAR AHMAD:** Very young yes, children.
 24 **MS FRASER BUTLIN:** And a fourth on the way.
 25 **MR WAQAR AHMAD:** My wife was heavily pregnant.

20

1 **MS FRASER BUTLIN:** You talk in your statement about how
 2 difficult that was for you, both having to keep
 3 separate.
 4 **MR WAQAR AHMAD:** Yes, from my family, from my kids and the
 5 rest.
 6 **MS FRASER BUTLIN:** I think you have also said you were
 7 very worried and frightened about what would happen to
 8 you?
 9 **MR WAQAR AHMAD:** It was the way we were told, you know, me
 10 and my wife, that, you know, that that would kill a nd,
 11 you know, the whole thing, the diseases and stuff a nd
 12 we have to keep away from -- I have to keep away fr om
 13 other people, and that's -- you know, when they sai
 14 that things, like, you know, you have to be away fr om
 15 the people in case people can catch this thing from
 16 you, and, you know -- so my kids was like, you know --
 17 I couldn't invite anybody to come to my house, and
 18 even some people they find out and they were just -
 19 they would be apart from us. And therefore it is n one
 20 of my fault or anything and I was going through har
 21 life.
 22 **MS FRASER BUTLIN:** When you were able to return home from
 23 the stroke rehabilitation unit, what was your life
 24 like as a family, as an immediate family?
 25 **MR WAQAR AHMAD:** Within the family it was very hard,

21

1 they just departed away from me.
 2 **MS FRASER BUTLIN:** You had been running your own business,
 3 very successfully.
 4 **MR WAQAR AHMAD:** Yes.
 5 **MS FRASER BUTLIN:** But you struggled to work?
 6 **MR WAQAR AHMAD:** Yes.
 7 **MS FRASER BUTLIN:** And the business failed?
 8 **MR WAQAR AHMAD:** Yes.
 9 **MS FRASER BUTLIN:** And so since then you haven't been able
 10 to work?
 11 **MR WAQAR AHMAD:** No.
 12 **MS FRASER BUTLIN:** You were then, in relation to the
 13 hepatitis C, too unwell and too weak to be treated; is
 14 that right?
 15 **MR WAQAR AHMAD:** Yes. Because then I start going to see
 16 with my step-sister to the liver specialist at the
 17 Freeman Hospital and very first -- first year she said
 18 I can't have it because, "You have a very weak body,
 19 so we can't give you any treatment". And the next
 20 year was the same thing. Not until my step-sister
 21 forced them that, "You have to do something about it".
 22 **MS FRASER BUTLIN:** And that happened in about 2003?
 23 **MR WAQAR AHMAD:** Yes.
 24 **MS FRASER BUTLIN:** Your step-sister asked why you weren't
 25 being treated?

23

1 especially to my wife. She was very heavily pregna nt
 2 with the kid and, in real terms, she doesn't want m
 3 to see the kids, to go near the kids in case. And we
 4 weren't being told that -- exactly what we should d o,
 5 what we should not, all we were being told from the
 6 specialists, "Try to be away as much as you can". It
 7 was hard life like, you know, not going -- living i
 8 same house and not going next to your kids, can't talk
 9 to your kids, can't, like, you know, love your kids
 10 and stuff. And especially my wife, it was very,
 11 very -- she was very sick and, you know, she was du
 12 for a baby in a month or so and the life, you know,
 13 was very, very hard and -- unbelievable we had a li fe
 14 like -- in those years. It was dreadful.
 15 **MS FRASER BUTLIN:** You also drifted apart from a close
 16 family member.
 17 **MR WAQAR AHMAD:** Yes.
 18 **MS FRASER BUTLIN:** Why was that?
 19 **MR WAQAR AHMAD:** It was like they find out, you know, he
 20 has hepatitis C and in those days, hepatitis C and
 21 AIDS, I don't know, they were thinking it is the sa me
 22 kind of thing. So should be away from this person.
 23 Right? And he is not only dangerous to himself and
 24 the kids but to other people as well. And all my
 25 immediate family and, you know, my very good friend s,

22

1 **MR WAQAR AHMAD:** Yes.
 2 **MS FRASER BUTLIN:** And I think there was some verbal
 3 discussion about that?
 4 **MR WAQAR AHMAD:** Yes.
 5 **MS FRASER BUTLIN:** What do you remember of that?
 6 **MR WAQAR AHMAD:** We were sitting in there and my
 7 step-sister was getting very annoyed with the thing s.
 8 Well, you know, I was -- keep telling her, "Just ta ke
 9 it easy", but she said, "No, well, you know, let me
 10 talk to her". And she said to us, she says, "I'm
 11 sorry, you have to give him the treatment", and she
 12 says -- she was a little bit -- I think it is come to
 13 in a rude way and then later on she did apologise, she
 14 says, "Oh well, because my mum wasn't well". But
 15 anyway, they did agree they will start giving me
 16 treatment for that.
 17 **MS FRASER BUTLIN:** And they gave you interferon only?
 18 **MR WAQAR AHMAD:** Yes.
 19 **MS FRASER BUTLIN:** But that -- you were very unwell with
 20 the interferon?
 21 **MR WAQAR AHMAD:** Yes. They give me for -- I think for
 22 just over ten months and it didn't work, and that u sed
 23 to make me -- I used to take it on Saturday and for
 24 whole five next days I was totally unwell. Total
 25 unwell with the temperature and the rest, yeah.

24

1 **MS FRASER BUTLIN:** That unfortunately didn't clear the
 2 hepatitis C. And how did you come to have your second
 3 round of treatment?
 4 **MR WAQAR AHMAD:** A year later again it was all to my
 5 step-sister who made them to, you know, give me
 6 another try.
 7 **MS FRASER BUTLIN:** So in 2003/2004 you were given
 8 interferon and ribavirin?
 9 **MR WAQAR AHMAD:** Yes, both.
 10 **MS FRASER BUTLIN:** And I think you said that you have
 11 never formally been told that you have cleared
 12 hepatitis C but just that your condition was better
 13 **MR WAQAR AHMAD:** Yes. On the second time when, you know,
 14 I -- I think it was given again for ten months or
 15 whatever, and she said, Professor -- I forgot her name
 16 again.
 17 **MS FRASER BUTLIN:** Bassendine.
 18 **MR WAQAR AHMAD:** Yes, Professor Bassendine. She says "It
 19 seems like you are getting better", and therefore they
 20 stopped that.
 21 **MS FRASER BUTLIN:** Since then though you have remained
 22 unwell?
 23 **MR WAQAR AHMAD:** Yes.
 24 **MS FRASER BUTLIN:** Partly because of the stroke.
 25 **MR WAQAR AHMAD:** Yes.

25

1 I get confused a bit, you know. And so we ask again
 2 and three time when my step-sister asked them again,
 3 they said they lost the paper, right? And then third
 4 time when she said, she wrote a letter to head of
 5 Newcastle, I can't remember his name, then we were
 6 given part of my records.
 7 **MS FRASER BUTLIN:** Initially you were told there's nothing
 8 there?
 9 **MR WAQAR AHMAD:** Yes.
 10 **MS FRASER BUTLIN:** Your step-sister persisted and got
 11 a few records?
 12 **MR WAQAR AHMAD:** Yes.
 13 **MS FRASER BUTLIN:** But there's very little of them?
 14 **MR WAQAR AHMAD:** Yes.
 15 **MS FRASER BUTLIN:** And there is no record of a blood
 16 transfusion in there?
 17 **MR WAQAR AHMAD:** I couldn't find this.
 18 **MS FRASER BUTLIN:** And there's nothing in the GP records
 19 either?
 20 **MR WAQAR AHMAD:** Yes.
 21 **MS FRASER BUTLIN:** But the records you have are very
 22 patchy and very limited?
 23 **MR WAQAR AHMAD:** Yes.
 24 **MS FRASER BUTLIN:** You applied to the Skipton Fund and
 25 were turned down?

27

1 **MS FRASER BUTLIN:** But in terms of your liver, what's your
 2 position been?
 3 **MR WAQAR AHMAD:** I was -- I was, like, you know, a few
 4 years I was okay, then I started getting unwell again.
 5 And again I didn't know what was happening and, you
 6 know, so they sent me back there. They did the biopsy
 7 again, second time, at Freeman Hospital, and this
 8 is -- I'm having a ... fatty liver disease and it's
 9 something to go with that.
 10 **MS FRASER BUTLIN:** Is it fibrotic liver?
 11 **MR WAQAR AHMAD:** Yes. Fibrosis.
 12 **MS FRASER BUTLIN:** You heard about the Skipton Fund
 13 through some voluntary work you were doing through
 14 LIVErNORTH?
 15 **MR WAQAR AHMAD:** Yes, I did.
 16 **MS FRASER BUTLIN:** So you applied for your medical
 17 records?
 18 **MR WAQAR AHMAD:** Yes.
 19 **MS FRASER BUTLIN:** In relation to your records, what were
 20 you told?
 21 **MR WAQAR AHMAD:** Well, we applied for my medical records
 22 because I was told I can go for the Skipton Fund. So
 23 we tried and they said, "Oh, well, you have to write
 24 to a hospital", which we did, and they denied giving
 25 my whole treatment days what I had with them. Sorry,

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1 **MR WAQAR AHMAD:** Yes.
 2 **MS FRASER BUTLIN:** Do you recall why that was?
 3 **MR WAQAR AHMAD:** They said there wasn't enough evidence of
 4 a blood transfusion given to me in UK and I did
 5 like -- didn't argue with them but I just said, "Look,
 6 you know, I was really young when I came in this
 7 country and, you know, if I got hepatitis C I got it
 8 because I had so many operations in Freeman Hospital
 9 and was given the blood". And they said, "Oh, well
 10 you know, you might have this in Pakistan". I said,
 11 "No, 14/15 year old, why would I have it?"
 12 So it was just a mix of ... yeah. It is very
 13 annoying but -- you know, when they try to blame to
 14 someone else. Yeah? Which is I think up to today
 15 still happens.
 16 **MS FRASER BUTLIN:** And the letter from the Skipton Fund --
 17 sir, we don't need to look at it, for your note -- is
 18 WITN4265003. It simply says:
 19 "With regret I must advise you that the
 20 application has been declined. This is due to the
 21 lack of supporting medical records confirming that you
 22 were treated with NHS blood."
 23 It is the standard refusal without records.
 24 Thank you.
 25 **MR WAQAR AHMAD:** Thank you very much.

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1 **MS FRASER BUTLIN:** Ghufrana Qureshi, you are here to speak
 2 about your late mum, Mehmooda Adib Khanum. Your mu
 3 was born in Pakistan, grew up there, got married
 4 there, and your sister was born in Pakistan in 1969
 5 **MS GHUFRANA QURESHI:** She was, yeah.
 6 **MS FRASER BUTLIN:** Then your mum came to the UK, with your
 7 sister, to join your dad?
 8 **MS GHUFRANA QURESHI:** Yes.
 9 **MS FRASER BUTLIN:** In 1970 or '71 your mum had a
 10 miscarriage and she was admitted into Staincliffe
 11 General Hospital.
 12 **MS GHUFRANA QURESHI:** She was.
 13 **MS FRASER BUTLIN:** Which is now Dewsbury District, within
 14 that Trust.
 15 **MS GHUFRANA QURESHI:** It is.
 16 **MS FRASER BUTLIN:** Your mum was in hospital for three to
 17 four days.
 18 **MS GHUFRANA QURESHI:** According to what she said, yes.
 19 **MS FRASER BUTLIN:** And she told you that she'd been there
 20 for a few days and required a blood transfusion.
 21 **MS GHUFRANA QURESHI:** Yes.
 22 **MS FRASER BUTLIN:** You were then born in 1972?
 23 **MS GHUFRANA QURESHI:** I was.
 24 **MS FRASER BUTLIN:** And there were then two further
 25 children, your two brothers?

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1 brother to England to have that operation here, while
 2 myself and my sister and my brother were living wit
 3 my grandparents.
 4 **MS FRASER BUTLIN:** So, because she needed some medical
 5 treatment, she actually returned to the UK, after y our
 6 dad died, to have that treatment in the UK?
 7 **MS GHUFRANA QURESHI:** Yes.
 8 **MS FRASER BUTLIN:** In the 1998 when she was under the care
 9 of the cardiologist and she was having the bladder
 10 problems, how did she come to know that she had bee
 11 infected with hepatitis C?
 12 **MS GHUFRANA QURESHI:** So, following the heart attack, we
 13 were having some follow-up appointments and I can't
 14 really remember whether it was the bladder appointment
 15 or whether it was the heart consultant, so I did ta ke
 16 mum, and you know when they go through the records and
 17 they double check this is the history of the patien t.
 18 So when they were going through the history, the
 19 doctor said that, "So your mum's got hepatitis C" -
 20 they first said something else, which I didn't
 21 understand, so then had they said, "So your mum's got
 22 hepatitis C", so I quickly challenged it and saying
 23 that, "No, she hasn't got hepatitis C and what is
 24 hepatitis C?" So then the doctor asked my mum, "Ha ve
 25 you ever had a blood transfusion?" So I turned to

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1 **MS GHUFRANA QURESHI:** Yes.
 2 **MS FRASER BUTLIN:** You lost your dad when you were 8 or 9
 3 from a heart attack when you were on holiday in
 4 Pakistan?
 5 **MS GHUFRANA QURESHI:** Yes.
 6 **MS FRASER BUTLIN:** Although you stayed there for a little
 7 bit of time, your mum decided to come back to Engla nd
 8 as a single mum to raise you here?
 9 **MS GHUFRANA QURESHI:** We did stay in Pakistan for some
 10 time and then we came back. And that's when mum,
 11 myself and my brother were here, and my sister and my
 12 younger brother were in Pakistan at that time.
 13 **MS FRASER BUTLIN:** Then in 1998 your mum had a heart
 14 attack?
 15 **MS GHUFRANA QURESHI:** She did.
 16 **MS FRASER BUTLIN:** So she came under the care of
 17 cardiologists?
 18 **MS GHUFRANA QURESHI:** She did.
 19 **MS FRASER BUTLIN:** Then she also had some bladder
 20 problems; is that right?
 21 **MS GHUFRANA QURESHI:** She did, but prior to that incident,
 22 you know, prior to that -- while we were living in
 23 Pakistan, mum came back to England because she had
 24 a kidney problem and she had some hard stones so it
 25 needed an operation, so she came back with my youngest

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1 mum, because obviously I was interpreting for my mu
 2 as well, so when I turned to mum and she said, "Yes ,
 3 I had a blood transfusion just before you were born".
 4 And that was the first time I ever heard about mum'
 5 blood transfusion or her having a miscarriage.
 6 Because in a south Asian community, talking about
 7 marriage, sex, miscarriages, it is not something ve ry
 8 common that they would talk about, so that was the
 9 first time I ever came across that information, tha
 10 mum had had a miscarriage.
 11 So she just said that, "Just before you were
 12 born I had a miscarriage". And I gave that
 13 information to the doctor and that information was
 14 just left there. So it was just mentioned in passi ng.
 15 It wasn't like -- the doctor didn't go into any
 16 details or anything like that.
 17 **MS FRASER BUTLIN:** Some further blood tests were then done
 18 and it was confirmed that your mum did have
 19 hepatitis C?
 20 **MS GHUFRANA QURESHI:** Again, those blood tests were not
 21 done in our knowledge. Following that appointment --
 22 I am assuming this, that it was the consultant who
 23 oversaw my mum who must have raised that mum has go
 24 hepatitis, and the only thing that the consultant said
 25 at the time that -- in her notes it says there was

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1 a blood test done in 1999 and it says that she had
 2 hepatitis, and we're talking about 2001 I think. S
 3 this is quite a few years down the line. And that'
 4 the first time we were even told that there was
 5 a blood test done in 1999, and that's when it was
 6 confirmed that she's got hepatitis. And nobody eve
 7 told mum or myself about that.

8 **MS FRASER BUTLIN:** Your mum was then referred to St James'
 9 Hospital for the hepatology care that she required,
 10 and you have said in your statement that the care was
 11 excellent from then on.

12 **MS GHUFRANA QURESHI:** I would like to say that, again, how
 13 that process started or who referred her to St Jame s,
 14 again that was not in our knowledge, because follow ing
 15 that appointment I am assuming that that consultant
 16 must have contacted another doctor to say that this
 17 patient is positive and that's how we got
 18 an appointment from St James's Hospital saying, "Yo ur
 19 mum's got hepatitis and she needs to come in for
 20 a check-up".

21 **MS FRASER BUTLIN:** Just to be clear there, you attended
 22 all the appointments with your mum, until the cancer,
 23 which we will come to later, but for appointments
 24 somebody attended with your mum?

25 **MS GHUFRANA QURESHI:** Yes. She was always accompanied by

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1 **MS GHUFRANA QURESHI:** Because my mum had already had
 2 a heart attack, so it started giving her some
 3 palpitations and it was interfering with her heart
 4 problem, so that was the reason why they stopped it.

5 **MS FRASER BUTLIN:** How did it come to be stopped?

6 **MS GHUFRANA QURESHI:** I can't really remember exactly but
 7 I think we went back and they did -- because
 8 obviously -- I think there was a letter sent to the
 9 St James's Hospital saying mum is having heart
 10 problems, and that's why they stopped it.

11 **MS FRASER BUTLIN:** Your mum carried on after 2005 being in
 12 okay health?

13 **MS GHUFRANA QURESHI:** She did, yes.

14 **MS FRASER BUTLIN:** Then in 2008 she was told she had liver
 15 cirrhosis. How did she react to that news?

16 **MS GHUFRANA QURESHI:** To be honest, mum didn't understand,
 17 neither did I, what cirrhosis meant. On questionin
 18 the consultant, they just said that it's when your
 19 liver gets hard and it doesn't start functioning, and
 20 they explained that, you know, "Your liver has, like,
 21 500 jobs to do, so it means that your mum's liver i
 22 not working to the capacity it should be".

23 **MS FRASER BUTLIN:** She then went back on the interferon
 24 and ribavirin.

25 **MS GHUFRANA QURESHI:** Yes.

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1 somebody from the family. Majority of the
 2 appointments I attended but there were a few in the
 3 beginning that my brother attended because I wasn't
 4 very comfortable driving to Leeds, due to the one-way
 5 system and everything, until I got a bit used to it.
 6 So there are a few appointments that my brother
 7 attended, but then the majority of the appointments
 8 I attended until mum was diagnosed by cancer.

9 **MS FRASER BUTLIN:** And a large part of that was because
 10 your mum's English was limited and she needed you a
 11 an interpreter as well as a support.

12 **MS GHUFRANA QURESHI:** And at that time I was working as
 13 a qualified interpreter for courts as well.

14 **MS FRASER BUTLIN:** But you're not clear, or the family is
 15 not clear how your mum ended up under the hepatolog
 16 team at St James's, it just sort of happened?

17 **MS GHUFRANA QURESHI:** Yes.

18 **MS FRASER BUTLIN:** In about 2005 your mum was started on
 19 interferon and ribavirin?

20 **MS GHUFRANA QURESHI:** She was.

21 **MS FRASER BUTLIN:** And she had six weeks of treatment, but
 22 then it was stopped?

23 **MS GHUFRANA QURESHI:** It was.

24 **MS FRASER BUTLIN:** Why was it stopped and how did it come
 25 to be stopped?

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1 **MS FRASER BUTLIN:** What happened with that treatment?

2 **MS GHUFRANA QURESHI:** When she was on that treatment,
 3 obviously it did take a toll on my mum. To be hone st,
 4 before she started the treatment I would say she wa
 5 quite fit and healthy. You know, despite having th
 6 heart attack and the bladder problems, she was alwa ys
 7 doing her on own -- she was very independent, doing
 8 everything herself, loved her gardening and
 9 everything, but since she started the treatment,
 10 that's when her health started to deteriorate, so i
 11 was a complete scenario where somebody goes for
 12 treatment to recover, it was like mum was a fit and
 13 healthy person, went for treatment and actually bec ame
 14 more poorly because of the treatment.

15 It did take a toll on her to the point that she
 16 would have -- just like the gentleman sat next to me,
 17 Mr Waqar, she would have her injection on the Thurs day
 18 and the next day she would have all the symptoms,
 19 aches and pains, mood swings, she would sleep quite
 20 a lot, and by the time she would recover from all
 21 those symptoms, it was time for her second injectio n.
 22 So it was one of those cycles that she would get ac hes
 23 and pains, recover and then it was a day later it
 24 starts all over again. So it did take the toll on
 25 her.

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1 **MS FRASER BUTLIN:** And the treatment was stopped at
2 43 weeks.
3 **MS GHUFRANA QURESHI:** It was, yes.
4 **MS FRASER BUTLIN:** Because the doctor rang and told you
5 she needed to stop immediately. Why was that?
6 **MS GHUFRANA QURESHI:** I used to give her all the
7 injections. So it was -- it was one of the evening s,
8 actually, it was, I think, like, 6/7 o'clock, it wa
9 quite late in the evening that I did get a phone call
10 from one of the consultants that mum used to see,
11 Dr Rehman -- I think it was Dr Rehman, I can't
12 remember exactly which one, so it was one of the
13 consultants from the team. So they just said that,
14 "We just want you to stop the treatments immediatel
15 because it is really fatal for your mum". So I was
16 quite shocked that, you know, something that I've been
17 giving something to her every week, how can suddenl
18 it's becoming dangerous for her? So they said to,
19 "Stop the treatment because it is really, really ba
20 for your mum, because her liver has started to" --
21 I understood that he's saying that it's decomposing .
22 You know? And when you think about decomposing, yo
23 think of something just going bad, really.
24 So I took the phone call, spoke to my sister and
25 I said the same thing, I said that, "They're saying

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1 I took my son at the time with me, and that's when
2 they said that she is having an assessment done for
3 a blood -- for a liver transplant. That was even more
4 shocking to think of a transplant. That means that
5 she's -- her liver has completely gone now. So she
6 was having her tests. I had -- my baby was crying as
7 well. I was quite emotional, like, you know, am
8 I going to lose mum?
9 **SIR BRIAN LANGSTAFF:** Just take a moment.
10 **MS FRASER BUTLIN:** Take your time.
11 **SIR BRIAN LANGSTAFF:** If you want a break, just ask.
12 **MS GHUFRANA QURESHI:** Because after losing dad, mum was
13 everything for us, and we are quite a close-knit
14 family. But mum pulled through that. She had all her
15 tests and everything. And after that we were
16 confident -- another meeting, that meeting was with out
17 my mum, it was myself, my sister and both my brother s,
18 and they just said that -- they talked about what
19 liver transplant is and what are the other options.
20 They explained that there are different ways of doing
21 the transplant: we can give her a full new liver, o
22 it could be that if the family is a match they can,
23 you know, take a segment of one of the healthy live rs
24 and transplant that and that will help your mum's
25 liver to sort of get better. And when it is family ,

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1 that mum's liver is decomposing so we need to stop the
2 treatment". My sister is a doctor and she explaine
3 that it is not decomposing, it is decompensation, and
4 that's -- I didn't even understand what that meant at
5 the time. But for me it more like: what have I don
6 wrong? You know, have I overdosed her? Have I don
7 something wrong? Because every week I was giving t he
8 treatment to her. And that's when the treatment wa
9 stopped.
10 **MS FRASER BUTLIN:** The treatment had also not cleared the
11 hepatitis C at that point?
12 **MS GHUFRANA QURESHI:** No.
13 **MS FRASER BUTLIN:** A short time later you attended
14 an appointment with your mum and were told that thi
15 was in fact a meeting about whether your mum could
16 have a liver transplant?
17 **MS GHUFRANA QURESHI:** Yes.
18 **MS FRASER BUTLIN:** What can you tell us about that
19 meeting?
20 **MS GHUFRANA QURESHI:** Again, you know, because mum was
21 having follow-up appointments regarding her blood
22 tests, you know, every week she would go for her bl ood
23 tests, nobody explained why we were going for that
24 appointment. I was assuming it's just another bloo
25 test that they're going to do and we'd be coming back.

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1 you would do anything for your family. And again,
2 maybe because we lost our dad at such a young age, mum
3 was everything for us. It was me and my brother, w
4 were like, "Yeah, yeah, we will go for it
5 straightaway". So, you know, she's -- and then the
6 explained, no, it is not just like that, you know, we
7 have to go through the procedures, but we will wait
8 and see what the MDT decide, and that was --
9 **MS FRASER BUTLIN:** The multidisciplinary team meeting.
10 **MS GHUFRANA QURESHI:** Yes. So, again, not understanding
11 what MDT means, again we asked them and they said i
12 is going to be a meeting where the specialists are
13 going to be there, the radiologist, the anaesthetist,
14 the heart doctor, they are all going to be sat ther
15 and they're going to make a decision whether your mum
16 is suitable or not for a transplant.
17 **MS FRASER BUTLIN:** Unfortunately at that MDT meeting it
18 was decided she was not well enough and would not
19 survive a transplant.
20 **MS GHUFRANA QURESHI:** Yes, the doctor's words were, "If we
21 do put her to sleep she may not come round."
22 **MS FRASER BUTLIN:** But in 2009 your mum's condition
23 improved. What can you tell us about that?
24 **MS GHUFRANA QURESHI:** Again, she went for her normal
25 check-up and everything. It was Dr Davis who saw m um

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1 and he was quite shocked himself, and he was like,
2 "I can't believe these results, you know, they are so
3 good. That means your mum's liver is getting better".
4 And I think it was just that news for my mum that m
5 liver is getting better, she just perked up suddenl
6 to a point where she was back to normal, her mood
7 swings was gone. I think that mentally not having
8 somebody to talk to, not having her husband there t
9 talk to, she wouldn't talk about her illness to us, in
10 terms of us children, you know, she wouldn't talk
11 about what she was going through or what she was
12 feeling. She kept all that quite personal to herself
13 maybe. So it was quite a relief for her that she w as
14 getting better.

15 So from that I don't know how -- whether it is
16 our prayers or whether it was the treatment, I don'
17 know, but she just suddenly started to get better t
18 a point that the doctor did say there is no point
19 telling her that she's still got the virus, we will
20 leave it to this point because she looks so good in
21 herself.

22 **MS FRASER BUTLIN:** So in 2016 your mum was still doing
23 well.

24 **MS GHUFRANA QURESHI:** Mm-hm.

25 **MS FRASER BUTLIN:** And she underwent treatment for the

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1 are you not agreeing for it?" So in the end she wa
2 convinced and she did go for the treatment.
3 **MS FRASER BUTLIN:** And she did better on that treatment
4 than she had before?

5 **MS GHUFRANA QURESHI:** She did. It had a lot less side
6 effects, yes. I would not say any, compared to wha
7 she had gone through.

8 **MS FRASER BUTLIN:** Then in 2018 one of her routine liver
9 scans showed a small tumour in her liver?

10 **MS GHUFRANA QURESHI:** Mm-hm.

11 **MS FRASER BUTLIN:** What were you told about that? And if
12 you would rather, I can read it from your statement .

13 **MS GHUFRANA QURESHI:** I think if you read it, please.

14 **MS FRASER BUTLIN:** Sorry, sir, there is two references to
15 it. I just want to make sure I pick up the right
16 reference.

17 **MS GHUFRANA QURESHI:** It is the Dr Jones one.

18 **MS FRASER BUTLIN:** It is.

19 **MS GHUFRANA QURESHI:** I didn't attend those appointments,
20 it was were attended by my sister and brother, and
21 there was an interpreter on the first appointment.

22 **SIR BRIAN LANGSTAFF:** That's paragraph 50.

23 **MS FRASER BUTLIN:** Thank you, sir.

24 "50. My sister and my brother, as well as
25 a professional interpreter, attended the follow up

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1 hepatitis C, but with the new direct acting
2 antivirals, not the injections.

3 **MS GHUFRANA QURESHI:** Yes. So what happened on that
4 occasion was that she was seen by a consultant who --
5 or a doctor who she didn't see before. So it was t he
6 first time. It was a female doctor. And the first
7 thing, they said that we have got a new treatment.
8 Mum, she didn't even -- she didn't go any further, mum
9 was like, "I don't want any more treatment". Becau se
10 obviously the first treatment had such a bad impact on
11 her health, her mood, the aches and pains. She was
12 always complaining that she has this metallic taste in
13 her mouth, which, when I spoke to the doctors, they
14 said it's due to the ribavirin tablets. And they said
15 it will be, but it wasn't as if it just finished, even
16 finishing the treatment she always had that taste for
17 quite some time.

18 So it was like, "Okay, this treatment has got
19 very less side effects, so we will let you have thi
20 treatment. And the doctor actually did say that,
21 "This is a very expensive treatment, we are not
22 offering it to everybody, you were one of the lucky
23 ones, it costs the NHS to about £30,000 to £40,000"
24 And I was like, "Mum, just go for it, you know, the
25 are giving you a treatment that is so expensive, wh

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1 appointment with my mum after it was confirmed to b
2 cancer. My mum was very upset and asked a lot of
3 questions. I did not feel able to attend this cancer
4 appointment as I could not cope with it at the time

5 "51. Dr Jones explained that it was pea-sized
6 and was not one of those cancers that would not
7 develop rapidly. They explained that it would take
8 roughly five years before my mum would experience a ny
9 dramatic changes ...

10 "52. At this time there were also meetings to
11 consider options such as radio ablation treatment i
12 which the doctors could use a laser to burn the
13 cancerous area. However, the cancer was located in
14 the middle of her liver, so the doctors decided tha
15 it was not advisable to go ahead with that plan."

16 In fact, your mum's condition deteriorated quite
17 rapidly and she developed encephalopathy and became
18 very confused and disorientated.

19 **MS GHUFRANA QURESHI:** To be honest, the encephalopathy --
20 I can't say this word -- the confusion status, she did
21 have it throughout her treatment, but then towards the
22 end it was getting very, very frequent, that it was
23 like from one hospital to the other, we were like -
24 one day we were in Dewsbury Hospital, then
25 Pinderfields or Huddersfield, so we were always tak ing

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1 her to hospital, because it -- she developed into
 2 a pattern where she would start getting very confused,
 3 very disorientated. Her speech would get slurred, her
 4 lips would droop a little bit, so you could tell that
 5 something's not right. That became a pattern that we
 6 could tell. And then the doctors started to give her
 7 some lactulose to get her bowels moving a lot more so
 8 that those toxins don't make her more confused.
 9 Those episodes were getting more and more
 10 frequent, to a point that it was getting very, very
 11 difficult for my mum as well because she would forget
 12 things. She would go in the toilet, leave the tap
 13 open. She'd left the gas open a few times. We had to
 14 put a few measures put in place for those things. So
 15 it wasn't just the treatment, it is all the rest of
 16 the things that happened because of the treatment
 17 then.
 18 **MS FRASER BUTLIN:** And you went with your mum to
 19 an appointment on 11 May at Pinderfields where she
 20 thought she was going in for a surgical procedure to
 21 remove a blockage but you were told that the cancer
 22 had spread to her lungs?
 23 **MS GHUFRANA QURESHI:** Again, because mum had -- she had
 24 a lot of oedema in her legs, you know, a lot of
 25 swelling in her legs, and then her tummy was quite

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1 **MS GHUFRANA QURESHI:** Yes.
 2 **MS FRASER BUTLIN:** And your sister, as you say who was
 3 a doctor herself, actually spoke with the doctor and
 4 you have described it as telling him off for how he
 5 had spoken to you, because she felt that what had
 6 happened was inappropriate?
 7 **MS GHUFRANA QURESHI:** Yes, because when I called my
 8 sister, I just said to her get to Pinderfields really
 9 quick and obviously, being a doctor, she was assuming
 10 a lot of things which I didn't even think about, so
 11 she just asked me, "Is everything okay?" I said, "No,
 12 just get here quickly". So she asked me, "Is it
 13 really bad?" Because I was told that mum might be
 14 just with us for a few hours or a day, I said, "It is
 15 even worse".
 16 **MS FRASER BUTLIN:** Do you want to take a break, Ghufra?
 17 **SIR BRIAN LANGSTAFF:** Let's take 5 minutes break, shall
 18 we?
 19 (11.03 am)
 20 (A short break)
 21 (11.10 am)
 22 **MS FRASER BUTLIN:** Sir, I am just going to read a number
 23 of paragraphs from Ghufra's witness statement and if
 24 Ghufra wants to add anything she is going to
 25 interrupt me.

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1 distended as well, the doctors came a few times at
 2 home and they did think that she might have a bowel
 3 blockage, so it would be better that she goes in to
 4 have that checked out and, if there is a blockage,
 5 they'll have to treat it immediately. That's what the
 6 intention was.
 7 She wasn't in the surgical ward at the time.
 8 When she went and had the scan, it was to check
 9 whether she had a bowel blockage which would need
 10 operating, and that's when it appeared that the cancer
 11 had spread, the cancer that we were told is a pea
 12 size, it won't spread for another five years, won't
 13 impact on her, and it had spread to her lungs.
 14 **MS FRASER BUTLIN:** And you were on your own when the
 15 surgical doctor told you? And he told you in a fairly
 16 blunt fashion?
 17 **MS GHUFRANA QURESHI:** Mum was asleep at the time. So I --
 18 you know, when the doctor came in, I just stood up.
 19 And he was very blunt in the sense in that he was
 20 like, "Well, I'm very sorry to let you know your mum's
 21 cancer has spread to her lungs and she can die with in,
 22 like, three days, and it could be a matter of hours or
 23 a matter of days".
 24 **MS FRASER BUTLIN:** You struggled to take that in, but you
 25 organised for your siblings to arrive.

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1 In your statement, Ghufra, you say this.
 2 "Following this, there were several doctors
 3 discussing with my siblings and me about next steps
 4 They were explaining the protocols, such as not
 5 resuscitating my mum. I could not even take in what
 6 they were saying at the time. One of the doctors
 7 said, 'I am telling you, your mum is not going to walk
 8 out of this hospital alive'.
 9 "62. I was in shock. I thought they were
 10 giving up on my mum. Either my brother or sister
 11 signed the forms, but I did not want to.
 12 "63. I asked the doctors to show me the scans,
 13 which showed she had five lesions on the lower lobe
 14 of her lungs. The cancer had spread throughout her
 15 lungs ...
 16 "64. We called my mum's brothers - my uncles,
 17 in Pakistan and relayed the news to them.
 18 "65. My sister kept looking at my mum, and ...
 19 said that my mum's current condition did not match up
 20 with what the doctors were describing. My brother
 21 advised my uncles in Pakistan that they should
 22 immediately travel to the UK, and I liaised for the
 23 provision of a hospital bed for her discharge, which
 24 was provided in a day.
 25 "66. She was discharged home with a referral to

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1 the palliative care cancer team. Mum knew about the
2 cancer but she didn't know about the spread and the
3 end of life prognosis. In her mind, she had gone i
4 with a suspected blockage and come home with a medical
5 bed and commode, so she did not understand why she had
6 been sent a medical bed and increased care package and
7 so she refused to sleep in the bed. She continued to
8 sleep in her bed downstairs at home. It wasn't until
9 she became so ill that she was prepared to sleep on
10 the bed.

11 "67. My mum knew something was not right, and
12 she would say so, but other than that, she let it go.
13 Her brothers arrived not too long after, and again my
14 mum questioned why they were here. We explained that
15 they were coming to spend Eid with us, but she kept
16 saying, why are they coming?

17 "68. She was suspicious about it even when they
18 arrived, coming without their wives. I think she knew
19 what was going on but none of us had the courage to
20 talk about it.

21 "69. My uncles ended up staying for three
22 months until my mum passed away. I think she lived
23 a lot longer because of my uncles being there with
24 her. They gave her the best three months of her life.
25 They were cracking jokes and laughing, recalling

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1 **MS GHUFRANA QURESHI:** Yes, because I didn't see this
2 evidence. When I left the form with the consultant,
3 they filled in the document, you know, the form, the
4 sections that they had, and they sent it directly to
5 the relevant place. So I didn't even know that the
6 put 1960 in there.

7 **MS FRASER BUTLIN:** If we go further down there, in (iv)
8 we do see that it is ticked that she had received
9 whole blood and there had been a transfusion during
10 pregnancy. That application was refused because there
11 were no records of a transfusion. And so you sought
12 records for your mum. There weren't any within the
13 hospitals available to you but you also applied to the
14 West Yorkshire Archive Service.

15 **MS GHUFRANA QURESHI:** I did.

16 **MS FRASER BUTLIN:** Why did you try them for the records?

17 **MS GHUFRANA QURESHI:** Because initially I didn't even know
18 about the Skipton Fund. I don't know if you might
19 come to it later, when I started doing some work with
20 The Hepatitis C Trust, that's actually when
21 I mentioned mum's story, you know, in terms of what
22 had happened to mum about the blood transfusion, and
23 it was actually an email that I was sent by The
24 Hepatitis C Trust. It's from Samantha, I know she is
25 in the room today. I had an email from Samantha

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1 memories from their childhood. It felt like my whole
2 family moved in with my mum during that time."

3 Your mum died on 21 August 2019 and you talked
4 in your statement of your ongoing grief and the huge
5 loss that she is to you.

6 I want to deal with one last topic with you,
7 which is the Skipton Fund. Your mum never received
8 any support from the Skipton Fund. In 2009 you
9 applied to the Fund. Can we look at the application
10 form.

11 WITN6946007. It is page 7 that I would like to
12 look at please.

13 This is part of the form that the Inquiry has
14 seen for many people applying, and we see there that
15 the date of when the infection probably occurred is
16 "[query] "1960s", then:

17 "Route of acquisition is unclear -- previous
18 transfusions in UK during pregnancy in the 1960s."

19 Was your mum even in the UK in the 1960s?

20 **MS GHUFRANA QURESHI:** No. She was in Pakistan and she was
21 single at that time.

22 **MS FRASER BUTLIN:** So your family are left somewhat
23 confused as to why it has been written in the form by
24 the doctor that there were transfusions in the 1960
25 in the UK?

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1 saying that, "You mentioned that your mum had a blood
2 transfusion and it was in the UK, and if it was in the
3 UK, please look at the Skipton Fund". So the
4 application form was sent by The Hepatitis C Trust.

5 So I don't know where all this came from. So
6 obviously initially it wasn't my responsibility to
7 look for the records. I was given a form, I've
8 completed the form, mum has given her statement to say
9 she had a blood transfusion and I left it on that.
10 Because there were no records, I had to get some more
11 evidence, because that's what the rejection letter
12 said, that there wasn't enough evidence as well. So
13 requesting from the archives was because mum's name
14 was spelled in quite a few different ways on her
15 passport: it is M-A-H for Mahmooda; in some spellings
16 she had M-E-H; somewhere she had Mrs Khanum; somewhere
17 it was Mrs Jameel, which was my father's name. So
18 because there were so many names, I had to send an
19 application to say, "Could you find the record of this
20 person with these names, with these spellings, and see
21 if you can find any blood transfusion records".

22 **MS FRASER BUTLIN:** I want to look at the email you got
23 back from the West Yorkshire Archive Service. It is
24 page 21 of the same document, please, Lawrence.

25 We see their response, that:

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"We only hold general admission registers of in-patients to Dewsbury hospital up to 1961. We have though no actual files of individual patients who attended this hospital. However we wonder if it was actually Staincliffe Hospital where your mother was admitted as maternity services had been transferred there in 1972. Again, unfortunately we have no patient records held here of that hospital for that period.

"We presume that registers covering those hospitals at the time may no longer survive if they have not been deposited in our service by this time. This is probably also the case for individual patient files for these hospitals. You appear to have been informed via the NHS trust that records only go back to 1975 that they now hold ..."

It is just to note the existence of registers of inpatients at hospitals in the Archive Service rather than necessarily within the NHS. Although they weren't able to assist you.

You appealed the refusal in 2010 and that was also -- the appeal was also refused.

MS GHUFRANA QURESHI: Mm-hm.

MS FRASER BUTLIN: If we could turn to page 11 of this document, we have the refusal letter. The first fe

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didn't know about anything else. So it wasn't something that, you know, she knew about. She didn't even know what hepatitis C was at the time. So, I only feel she wasn't believed. Just because people in Pakistan with genotype 3 have hepatitis doesn't mean that mum contracted it from Pakistan -- when she has had a blood transfusion and there is a statement, which I did pass on, where mum goes into a lot of detail saying, "I was admitted in hospital, I was there for three days, my doctor was (unclear)", you know, she knew all the details, you know, exactly when and what happened. So just by saying that, you know, she's got it from Pakistan means they are not believing her, they're not believing she got the hepatitis C from UK. They are not saying that she had the blood transfusion, and it means that they are not believing her just because she is from a Pakistani background.

MS FRASER BUTLIN: For your note, sir, there is a statement that Ghufra has translated and it is all signed and written down. It is on page 14 of this document. So it is the same URN but page 14.

I want to pick up your work with The Hepatitis C Trust in our thematic discussion, if I may. And I'm conscious of the time. Sir, I wonder if we take

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paragraphs are the standard refusal, but if we turn over the page, page 12, it is the second and third paragraphs and this is the substance of the refusal. "It would be unusual for a person to be given a blood transfusion after a miscarriage in the absence of any particular circumstances that would make it necessary. There is no evidence of any as much circumstances in your case. In addition genotype 3 Hepatitis C with which you are infected is 90% prevalent in Pakistan (as opposed to 50% prevalent in the UK). This suggests that you may well have been infected in Pakistan before arriving in the UK.

"As a result of these considerations we are not satisfied that it is probable that the infection resulted from NHS treatment and accordingly regret that we must refuse your appeal."

In your statement you feel you have said you feel like no one believed that your mum had contracted the hepatitis C in the UK from her blood transfusion. Do you want to tell us anything about that?

MS GHUFRANA QURESHI: It's because why would mum say that she had a blood transfusion when it was asked as a passing -- you know, that, "Have you ever had a blood transfusion?" Mum said that at the time. At the time we didn't know about the Skipton Fund, we

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a break now and then return for a discussion across the whole panel?

SIR BRIAN LANGSTAFF: Yes. Let's take a break until 11.50 am.

(11.21 am)

(A short break)

(11.50 am)

SIR BRIAN LANGSTAFF: Yes.

MS FRASER BUTLIN: Thank you. I want to spend a bit of time now with all three of you discussing some thematic issues that have arisen in your evidence.

First of all, do any of you have any reflections on whether being part of a minority ethnic community has had any impact on the treatment you or your loved ones have received from clinicians?

Regina, I don't know if you want to start?

MS REGINA CHEPTANUI: Can you repeat the question?

MS FRASER BUTLIN: Of course. Whether being from a minority ethnic community has affected the treatment you have received or the communications you have had with clinicians, people in the hospital?

MS REGINA CHEPTANUI: Yeah, I find out that being black or being minority, because we are all different, when you say anything to doctor, he seemed to change his mood and -- either if it is medication, he will start,

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1 like, talking to you like you are a child, you haven't
2 got no common sense. And I think that is wrong
3 because we are all human and they haven't got
4 compassion. To me, since I -- since they say -- start
5 treating me with this viral, this hepatitis C, I find
6 out, oh, the nurses have more compassion than the
7 doctors. I never met my Dr Wright face to face, but
8 even by him writing to me letters or refusing to sign
9 my form, it is like: you don't get a right, Regina,
10 this don't belong to you, belong to people in this
11 country.

12 But I did have blood transfusion, so why can't
13 you say, "Maybe you caught it from here or maybe you
14 caught it from Kenya"? As well, when I think of it
15 when I was younger, we were under British until 1963.
16 So who gave me BCG? It is the British. So he should
17 not judge me like I'm a child that -- or I don't know
18 nothing. We are all equal in God's eyes.

19 **MS FRASER BUTLIN:** Waqar, Ghufrana, do you have any
20 reflections on that?

21 **MR WAQAR AHMAD:** Yes, absolutely. Yes. Ethnic minority,
22 especially from India, Pakistan, Bangladesh;
23 Asia people, as most of their first language has no
24 been English, I think they have been let down, they
25 have been let down quite a lot. Yeah? And when

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1 they are talking to?

2 **MR WAQAR AHMAD:** Yes.

3 **MS FRASER BUTLIN:** Ghufrana, do you have any reflections?

4 **MS GHUFRANA QURESHI:** Yes. I would like to say that
5 I think in terms of the doctors, they didn't show a
6 attitude that mum came from Pakistani background or
7 anything like that, but, looking beyond that point,
8 they did have in their head, or they did have it in
9 their mind that she was from Pakistan so that means
10 she's got it from Pakistan, so maybe that came across.
11 But what I would like to highlight is that nothing was
12 put in place as a support for mum.

13 So if you think about it, yes, we were mentioned
14 that there is a buddying system, that was from St
15 James's Hospital directly. When I did inquire, you
16 know, what is the buddy system, there was nothing in
17 place for anybody who couldn't speak English. Mum was
18 never offered -- never offered -- counselling.
19 Whether she took it or not, that would have been
20 a different scenario, but she was never offered
21 counselling pre-treatment, post-treatment, going
22 through cancer, never.

23 As a family, we were going through it as well,
24 we were never offered any counselling, any support.
25 There was nothing put in place. Whether that was

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1 I see -- when I go back and see that, a lot of -- soon
2 after I recovered a bit, I start working with the
3 liver people and try to take them to the hospital,
4 talk on behalf of them and stuff, you know, and a lot
5 of times they have been given a lot of refusal from
6 the hierarchies, from the doctors and that thing, and
7 they have been let down a lot.

8 It is not -- have I been let down by the -- by
9 that? I think I have been let down. And if my
10 step-sister would never come to rescue me, I wouldn't
11 have been given that treatment what I was given.
12 Because my step-sister was English, white, majority
13 and they will listen more to her than to me, you know?
14 And I think since has things gone better? I think it
15 has gone a bit better, but, you know, not the same
16 what would we accept from -- expect from the doctors.
17 No. And we have been let down, you know, a lot of the
18 time by them. But things are getting a bit better.
19 And a lot of -- I have seen a lot of people been let
20 down by the doctors and stuff, you know?

21 **MS FRASER BUTLIN:** And that work you have been doing is
22 through LIVERNORTH.

23 **MR WAQAR AHMAD:** Yes.

24 **MS FRASER BUTLIN:** You have accompanied others with liver
25 conditions to try to help them with the clinicians

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1 because we come from an ethnic minority, because no
2 when I look back, you know, there's lots of support
3 groups, there's lots of peer support, there is a lot
4 happening now, but why not for the BAME community?
5 Why not for people who don't speak English? Why not
6 for people who come from a background or come from
7 a country that they don't know what is available?
8 Nothing was put in place.

9 **MS FRASER BUTLIN:** And in terms of the financial
10 assistance schemes, so the Skipton Fund and the EIBSS,
11 do you have any reflections on the impact of coming
12 from a minority ethnic community on your engagement
13 with them?

14 **MS GHUFRANA QURESHI:** For my mum's case it was bang in the
15 face, wasn't it, that: you come from Pakistan, it is
16 more prevalent in Pakistan, so your genotype C is
17 because you might have got infected from Pakistan. So
18 it was like the doors are shut you on there and then.
19 And my mother was very independent, she lived her life
20 with her own principles. Money wasn't something that
21 she was going for. I do remember I was more
22 challenging it, to say, "Mum, we will apply again, you
23 know, we'll get more evidence", and she was like,
24 "Just leave it". You know, "Just leave it". So she
25 didn't want to pursue it any further because it was

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1 like as if she was feeling that, "I don't want anybody
2 to judge me that I'm going for the money". So it
3 wasn't that personal financial gain there. It was
4 more for me to accept what has happened, that she had
5 been given a transfusion, she had hepatitis,
6 cirrhosis, cancer, the whole lot, and nobody is there
7 to take that accountability.

8 **MS FRASER BUTLIN:** Do either of you want to tell us your
9 experiences?

10 **MS REGINA CHEPTANUI:** My experience with applying for
11 funds, I was told straight -- when my Dr Wright signed
12 the form, I never saw it. Then I was turned down.
13 And at that time it was 2020 lockdown, so I didn't
14 apply in time -- reapply in time. So they say now you
15 have to fill the form again from -- to start again.
16 And I did that. I asked for the form. They sent me
17 forms and then I filled my part, and the other part
18 which was supposed to be Dr Wright to sign, I recorded
19 delivery letter all the way to him to sign and he
20 never replied me. As he's professional, he should
21 reply me, and he never replied. I still got a receipt
22 for when I sent it to him. And then I was ringing
23 them all -- ringing his office most of the time and
24 the reply was, "Oh, he is going to ring you back", but
25 he never.

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1 who were born after the transfusion. I was the one
2 who was looking and checking and asking them, "Go and
3 check with your doctor if you have this hepatitis C".

4 So this fund, I never got it. And then one day
5 I saw Samantha on the television and they were talking
6 about people who had been rejected not to have the
7 fund, and that's how I end up again repeat -- applying
8 again, because of their help.

9 So, I did apply again, and this time I had text
10 from my doctor, after Samantha, and -- I can't
11 remember her name -- Susan got in touch with my doctor
12 to say to them they have to sign this form because it
13 is not up to him to make that decision, if I can get
14 it or not. And I don't know what they said to him,
15 and I was in Asda doing my shopping and suddenly a
16 text came on and I read the text and the text said
17 that -- I can't remember all of it, but it is still on
18 my phone -- that Dr Hutton has agreed to sign my form
19 and can I bring the form back to surgery? And I was
20 in tears in Asda. I was so happy that at last
21 somebody agreed to sign my form.

22 And that was in June, I think June 28. And then
23 I think it was Sam or -- why am I forgetting her name?

24 **MS FRASER BUTLIN:** Susan, I think.

25 **MS REGINA CHEPTANUI:** Susan, who rang me by accident, not

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1 So last day was when I was told that, "Oh, you
2 cannot get this fund, this fund don't belong to people
3 who receive hepatitis C from overseas".

4 Then I said to him, "How about people who
5 receive blood transfusion? Because I received blood
6 transfusion here."

7 And he said, "No, your G4 type is not found in
8 this country, only in Africa."

9 So then I asked -- I rang the people who
10 supplied -- who gave this fund and I said to them my
11 doctor refused -- hepatologist refused to sign my
12 form, and they said to me, "You can ask your doctor to
13 do it". So I asked my doctor. So I got another ne
14 form, I asked my doctor to fill it in, and he refused.
15 He said to me, "It is only specialist, Dr Wright, who
16 can fill your form". So I was back and forward. And
17 all the time they are giving me the same letter,
18 saying that it is a copy of the letter which Dr Wright
19 sent to my surgery, saying that I'm not entitled to
20 this fund.

21 So I stop and I say, "Well, I'm not after the
22 money but if there's any help I can get, because I
23 not getting no help from doctors, I'm not" -- I never
24 even one day been asked, "How do you feel?" Or asked
25 how is my children who were born -- the two children

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1 knowing what's happened, and I was so over the moon
2 saying, "Oh, the doctor says I can take my form in, he
3 is going to sign for me", and I -- whoa, she was
4 happy, because I had been going through this with
5 them. And then suddenly, on 29 June, another text
6 came, in the morning time, saying, "My apologies" -
7 this was the secretary -- "My apologies", that
8 Dr Hutton has refused to sign my form. And I was so
9 upset about it. I cried. And I thought: why are they
10 playing with my life? Because you can't tell
11 somebody, "Yes, I will do it", and then suddenly
12 you've changed your mind.

13 So to me I start suspecting that he's -- they
14 were talking together with Dr Wright, because the -
15 all he put inside my form and said, "You can -- we are
16 going to post it to you", is the same letter from
17 Dr Wright. So, to me, I feel that they are playing
18 with my life. It is better to say to me, "I'm not
19 doing it", than having to say, "I'm going to do it"
20 and then suddenly you've changed your mind. Who do
21 you think you are? You should not treat me like
22 a child. Even I wouldn't do that to my children.
23 I wouldn't say to them, "I'm going to give you this",
24 and then change my mind.

25 So there must be something between them which

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1 I find out, because when he said he would sign my
2 form, he did say, "And I will find more notes to
3 support your claim". So what is this other thing that
4 they haven't told me or shown me about my -- what he
5 is saying, "There are more things -- I will look for
6 other evidence in the letters in your file to add into
7 your application form"? And then suddenly change his
8 mind.

9 **MS FRASER BUTLIN:** We spoke about it earlier, but because
10 you'd had a BCG in Kenya, then that was the reason for
11 the refusal by the Skipton Fund?

12 **MS REGINA CHEPTANUI:** Yes.

13 **MS FRASER BUTLIN:** Waqar, do have you any reflections on
14 your interactions with the funds?

15 **MR WAQAR AHMAD:** Yes. It did impact a lot, right, but by
16 saying that, like, does it -- you know, what I would
17 like to say is, like, my wife is -- has impact a lot
18 on my family and especially on my wife. She --
19 whenever -- a couple of times she has applied for --
20 maybe for insurance reason and she has to fill
21 a form -- but -- am I going out of the way? I don't
22 think I am going out of the way. Anyway, you know,
23 she had -- on certain question conferences or have you
24 been ever tested for hepatitis C? And she marks: yes,
25 I have been tested for hepatitis C. They don't ask

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1 refused because you were born in Pakistan.

2 **MR WAQAR AHMAD:** Pakistan. That's a stigma attached with
3 that, because you were born there, and "You can't have
4 this, you can't have that", you know?

5 It is sad, like, but this is what is happening,
6 you know. We have moved on but still there is
7 a stigma attached with us, like, you know, being as
8 an ethnic minority groups, yeah.

9 **MS GHUFRANA QURESHI:** I was just going to add to that. In
10 terms of the Skipton Fund, when mum's application was
11 rejected the second time and I called again to say,
12 you know, "I have given the evidence I can get, I have
13 tried to get them from the archives, I can't get
14 anything else, what else can I provide you to make you
15 realise she has had a blood transfusion?" And the
16 gentleman, I won't mention his name, but, you know,
17 what he did say was that, "Has your mum got any
18 friends that you can get a statement from, from that
19 time, that can recall that mum had a blood
20 transfusion?" And it boggles my mind that the
21 patient, the person having the blood transfusion, has
22 given it in writing, she signed it, I signed it, I've
23 translated it, you are not taking that on board but
24 you are okay to take another person's statement to
25 consider that, yes, she's had a transfusion. Why not

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1 you why have you tested for hep C. And they said for
2 so many reasons from them: we can't have you as a --
3 because you have been tested for hepatitis C, and we
4 can't -- you can't have insurance for so many reasons,
5 life insurance or that insurance or that insurance.
6 So it is a big impact on my family rather than me.

7 Then, again, you know, Skipton Fund -- has it
8 affected me (unclear)? Not really, but, you know, it
9 has on a lot of other people, as I have been working
10 with the LIVErNORTH for years and years and years,
11 yeah, and it does affect because of you are -- where
12 you belong and where you -- you know, if, like, you
13 know, ethnic minority, it does affect. It does
14 affect. Honestly speaking, it does affect on them,
15 right, because you are only certain -- belong to
16 a certain group, right? And as I said previously
17 that, you know, I have a -- like, you know, my
18 step-sister is prone to say that, and she has been
19 telling me, "Oh, go forward, go on, go on, right, you
20 deserve for this, you should get this, you should get
21 that, you deserve for this". But, you know, fairly
22 speaking, its effect on ethnic minority, they have
23 been treated differently than to the other
24 communities, yeah.

25 **MS FRASER BUTLIN:** Because your application was also

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1 the patient themselves, that -- the person who's
2 saying that, "I've had a blood transfusion", why are
3 you not taking that on board? Would it have been the
4 same if I was a white British person applying and I
5 would have put my foot down, would that have been
6 accepted? Or just because she was somebody who
7 couldn't speak the language, I was translating what
8 she was saying and it wasn't taken on board more
9 seriously the way it was.

10 **MS FRASER BUTLIN:** Your mum actually decided not to get
11 those statements from her friends, because she didn't
12 want to make a fuss. You said in your statement that
13 your mum was actually very fortunate that there wasn't
14 a significant difficulty within her close community
15 about her hepatitis C but that you have done some work
16 with The Hepatitis C Trust within the Pakistani
17 community particularly and hepatitis C.

18 **MS GHUFRANA QURESHI:** I have.

19 **MS FRASER BUTLIN:** Can you help us with your reflections
20 are of hepatitis C within the Pakistani community and
21 what you have seen in terms of how it impacts people
22 within their communities.

23 **MS GHUFRANA QURESHI:** I got in touch with The Hepatitis C
24 Trust after mum had gone through her second treatment
25 and I thought, "Well, I've enough knowledge there that

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1 support other people", because mum didn't get any
 2 support, there was no counselling, no information
 3 shared, because of the language barrier. I was an
 4 interpreter, a qualified interpreter at the time --
 5 well, I still am -- and I knew that there is -- tha
 6 value as well, so that was my main reason, to give
 7 something back to my own community, to make them aware
 8 about hepatitis C. But when I started doing a lot of
 9 work, I actually learnt things from The Hepatitis C
 10 Trust. I trained up to be one of their health -- you
 11 know -- is it health adviser? I can't remember what
 12 it is called. They were delivering some health day
 13 where they were explaining what hepatitis is, you
 14 know, what you should be eating, you know, how can you
 15 change your diet, do exercise. Things that the
 16 doctors should have been telling mum. It came from
 17 the Trust rather than the hospital.

18 My awareness sessions, I used to go out -- we
 19 did some testing on the hepatitis C bus, testing where
 20 it was just taking swabs to check whether anybody has
 21 antibodies. And we used to go to the Malters(?),
 22 which is more like a concert type thing, where lots of
 23 people will be there, lots of stalls, music, it's --
 24 it's got a very positive vibe, so we used to have the
 25 stands there and try to engage with Asian community

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1 that problem of stigma in the community?
 2 **MR WAQAR AHMAD:** Yes. A lot, yes. One thing is like, you
 3 know, if I'm going to see my doctor, right, the -- and
 4 I said I should have been -- "You should have been
 5 doing this", right? It wouldn't affect anything. But
 6 once my step-sister come with me and go and tell the
 7 doctor, "He needs this and you should be doing that",
 8 I don't know why, she will do it. My doctor will do
 9 it. But when I go, even though my English is not bad
 10 as like -- you know, I shouldn't be saying anything
 11 bad about anybody, about English barrier and stuff
 12 like that, but it did affect on doctor and -- and the
 13 other people when my step-sister come with me or when
 14 I go talk to the doctor; it make a big effect on
 15 doctor. Why does it affect on doctor? I still don't
 16 understand. Being as a doctor, you've got a degree of
 17 this, this, this, and you've been told to be equal,
 18 you know? But a lot of times it hasn't been
 19 happening. It hasn't been -- and still.

20 **MS FRASER BUTLIN:** Within the Pakistani community, your
 21 own friends and neighbours, what effect has the
 22 hepatitis C had on your relationships with others in
 23 the Pakistani community?

24 **MR WAQAR AHMAD:** Well, it is a stigma attached with hep C,
 25 right? Hep C, they don't want to come out and --

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1 and say, "Come on, just have your swabs done, it is
 2 going to take a couple of minutes", and people were
 3 reluctant and it was back to what was discussed
 4 before, because it is classed as -- because it is
 5 linked with HIV as well, because it is linked with,
 6 "Oh, it's a bad disease, you're going to spread it" --
 7 similar to what you were saying, not -- I do know
 8 a lot of people in Pakistan do have those
 9 misconceptions, that, you know, they are going to pass
 10 it on if they're going to sleep with their partner, or
 11 they can pass it on to their children, plates were put
 12 aside. You know, these were the things that the
 13 community were saying. So we did do a lot of work in
 14 the mosques, on the Malters(?), you know, general
 15 awareness at events.

16 And it was quite scary to think that, you know,
 17 why are the people not coming forward? It is because
 18 of the taboo. It is because of that stigma attached.
 19 And then being from a BAME background, being from
 20 an Asian or minority background where language is also
 21 a barrier, not understanding what's the process, no
 22 understanding the disease, not understanding the
 23 illness, the side effects; there's a lot more barriers
 24 than we are sort of touching on.

25 **MS FRASER BUTLIN:** Waqar, do you have any reflections on

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1 like, to learn hepatitis C is lot more than -- you
 2 know, you've got to understand what hep C is. But
 3 they don't want to come out and to learn what is the
 4 difference between hepatitis C and AIDS. They --
 5 loads of time they think it is AIDS and hepatitis C
 6 I mean, I feel sorry for the people who have AIDS,
 7 honestly speaking, you know, what they go through. It
 8 is a very, very hard life they are having. Well,
 9 hepatitis C is the same. Like, you know, in my
 10 community, if I say, "Oh, well" -- if they say, "Oh
 11 well, he has got hep C", and -- they don't want to
 12 learn where and why I've got a hep C, and that can be
 13 treated, it is very hard -- it's very hard in our
 14 community to learn. It should be learning but, you
 15 know, we're a little bit behind.

16 But, you know, things are getting better.
 17 I will say, yes, they are -- sure they are getting
 18 better, with knowledge with people and stigma
 19 attached, oh, the hepatitis C kills you. Well, it is
 20 a killer disease, it's -- you know, but if you have
 21 been affected with it and, you know, treated on the
 22 right time, right way, yeah.

23 **MS FRASER BUTLIN:** Regina, you mentioned in your evidence
 24 a feeling of stigma within your community as well. Do
 25 you want to tell us anything more about that?

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1 **MS REGINA CHEPTANUI:** Yes, the friends I had before,
 2 really they are no longer my friends because I have
 3 this hepatitis C. And first they ask what it is.
 4 I say it is a blood transfusion I was given. But I
 5 the language they think you've got HIV. But even I
 6 I -- I was lucky I didn't have HIV, because I was
 7 given blood at that time, but I don't really -- apart
 8 from my church and my children, I try not to say
 9 nothing to anyone. But I feel that even to have
 10 social life, I can't. Because I have to be -- to
 11 speak the truth, to tell people. If I'm going out
 12 with them, I will say to them, "Oh, I was diagnosed
 13 with hepatitis C because of blood transfusion", the
 14 I feel I can't tell people that because I think the
 15 will put me aside completely.

16 So I rather suffer silence. Only my children
 17 and their family knows. But I don't like talking too
 18 much about it because I still feel that it's something
 19 I didn't do it knowingly. If it was something I do not
 20 knowingly then I can take that blame, but I didn't
 21 know. So the only people I talk to when I feel low
 22 a bit, not my doctors, only Susan and Sam, because --
 23 it is easier, because they said to me, "We are just at
 24 the end of the phone", and to me they are my life
 25 saving because they show me and they help me to do

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1 with.
 2 But then, on the other hand, whoever did mum's
 3 blood test -- it is not a routine blood test, so
 4 I don't know how that happened, so nobody conveyed
 5 that message back. So those barriers need to be
 6 overcome as well, like the professionals need to
 7 convey the message in a proper way, so that the
 8 patient knows what's happening. And if they can
 9 understand how to treat somebody or how to respond to
 10 something, then obviously the community will
 11 understand better. Because if somebody goes to the
 12 doctors, if the doctors don't know what hep C is, how
 13 do you expect the patient to know?

14 **MS FRASER BUTLIN:** Do either of you have any thoughts on
 15 how communities might be supported to understand
 16 hepatitis C better?

17 **MR WAQAR AHMAD:** Yes, you know, I'll just -- I take you
 18 back. After I had hepatitis C, you know, and going
 19 back to my doctor -- to my dentist, right, and he
 20 found out, like, I had a hep C and, you know, he
 21 refused to treat me, my dentist, and he said, well,
 22 I needed to go to a dental hospital because he can't
 23 treat me. I did say to him a couple of times before,
 24 "Why can't you do it?" I mean, you know? He says,
 25 "I'm sorry, we can't treat you because you are

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1 things which I didn't want to do.
 2 I was very active person, I was outgoing person.
 3 When I was young I was doing all the sport, I was
 4 taking part in Kenyan sports. And now I don't feel
 5 even to do my knitting. I used to do knitting with
 6 the knitting machine, but I don't. All my comfort now
 7 is my Bible, because I know God is love.

8 **MS FRASER BUTLIN:** Do any of you have any thoughts on how
 9 those barriers and the stigma within your communities
 10 might be tackled and challenged and addressed? Do you
 11 have any thoughts of what might change things?

12 **MS GHUFRANA QURESHI:** I think professionals need to know
 13 as well, because, like, I remember when mum was
 14 positive, round about 2009, I went to the doctors
 15 myself, to my GP, because -- I've got eczema,
 16 obviously my skin can flare up quite bad at times, and
 17 I was mum's carer as well at the time, so when I went
 18 to the GP and I requested to have a blood test done
 19 for hepatitis C, and he was like, "Why do you want to
 20 have this blood test done?" And I had to explain why,
 21 which -- if you consider that I went there, it just
 22 needs to be regarding me, that I am asking for a blood
 23 test. Because it is not a routine blood test. But
 24 then I have to explain that mum is positive, that's
 25 why I need to have mine done, which they did go ahead

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1 a hepatitis C patient and you have to go to the
 2 hospital".

3 And seeing it is, like -- you know, it's
 4 affecting a lot on my community, right? Being as a
 5 hepatitis C. Right? And I think we have to --
 6 certain people have to come out to help us, right?
 7 Even though we should be helping each other. But
 8 I can say hierarchy people should come out and talk
 9 about hepatitis C clearly: what does it affect and
 10 what doesn't it affect on people.

11 **MS GHUFRANA QURESHI:** I think it is part of the
 12 understanding that it is a blood-borne virus. That
 13 never gets mentioned. Nobody told me or mum that, you
 14 know, you need to be careful when she goes for blood
 15 tests or -- you have mentioned the dentist. That's
 16 why it's -- just recalled that. Nobody told me that
 17 I've got to tell the dentist, I've got to tell the
 18 staff that were taking the bloods and stuff. It was
 19 actually my own sister who said that, "Whenever you
 20 take mum, just let the professionals know that, you
 21 know, mum's positive", and then they would put the
 22 sticker on, the highlighted yellow sticker to say, you
 23 know ...

24 But why did I have to go around telling
 25 everybody?

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1 Again, it is, like, that is the main cause. You
2 know, like, if people don't know, you are going to
3 spread it more. Hepatitis C Trust is doing so much
4 work that that awareness is there, but then
5 professionals need to be trained up a lot more.

6 **MS FRASER BUTLIN:** Regina, do you have any thoughts?

7 **MS REGINA CHEPTANUI:** I think we should really have
8 education for -- even in school, telling children,
9 because even little children, some of them got
10 hepatitis C and they get stigma. So it is good to
11 explain to people that hepatitis C is not that
12 dangerous. You cannot catch it just by shaking hands.
13 It has to be blood transfusion. Because if they know
14 that, then they won't segregate other people because
15 of hepatitis C.

16 **MS FRASER BUTLIN:** Sir, those are the questions I have for
17 the Panel. Is there anything you would like to raise?

18 **SIR BRIAN LANGSTAFF:** There is just one thing I would like
19 some more details of, and it is from Regina. It is
20 about your BCG in Kenya. Where were you living in
21 Kenya at the time?

22 **MS REGINA CHEPTANUI:** I was living in Kenya, I was born in
23 Nanyuki. I don't know if you know Nanyuki. But
24 that's when -- when I went to school, we were told --
25 you know, we were under British -- and we were told we

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1 forgetting her name -- I could apply for this fund,
2 because it is only by watching television and I saw it
3 and suddenly I took the number straightaway and
4 I said, "I have to find out how I can get this help".
5 All I rely on -- I don't want too much, whatever it is
6 they give me, it is okay, because I -- I receive my
7 pension, occupational pension, and I receive my
8 working pension. So it is only I will get less what
9 I had because I retire medically. I did not retire on
10 my retirement age.

11 I think when doctor say, "No, you are not
12 entitled for it", and the people who are supposed to
13 make judgment, they are not getting that form because
14 he don't want to sign, I think that's bad. And
15 I can't tell him to do it, I can't force him because
16 I'm the underdog and he is the hierarchy, because he
17 is a doctor and I'm nothing, I'm a patient.

18 And what they done to me -- I feel the last one
19 was the worst even to treat me like, "I will sign your
20 form", and then suddenly change their mind. That's
21 not the way to treat people, human beings, we are all
22 equal.

23 **MS FRASER BUTLIN:** Waqar, is there anything else you would
24 like to say?

25 **MR WAQAR AHMAD:** Yes, you know, particular to the

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1 were going to have the BCG done, and we would queue
2 and -- waiting for these doctors or qualified people
3 to give us BCG, and then we would be checked again in
4 two weeks' time. If it hasn't swollen then you have
5 to have another one. But if the needles were dirty
6 who knows? I don't know. All I knew that they are
7 going to protect us from tuberculosis and all
8 different infections. So we had no choice to say no.

9 **SIR BRIAN LANGSTAFF:** Do you know if any of your
10 classmates from school have got hepatitis?

11 **MS REGINA CHEPTANUI:** No, because I left Kenya in 1972,
12 and after school we all went separate ways. So
13 I don't know if they -- because some of them, they
14 never got tested or given blood, so I don't know.

15 **SIR BRIAN LANGSTAFF:** You haven't kept in touch?

16 **MS REGINA CHEPTANUI:** No.

17 **SIR BRIAN LANGSTAFF:** That's all that I wanted to ask.

18 **MS FRASER BUTLIN:** Regina, is there anything else you
19 would like to say before we finish today?

20 **MS REGINA CHEPTANUI:** Yes, before we finish today I would
21 like to say that we should not be treated like we are
22 nothing. Because to me I feel that, up to today, I
23 I didn't have Samantha and --

24 **MS FRASER BUTLIN:** Susan.

25 **MS REGINA CHEPTANUI:** Susan. I don't know why I keep

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1 Skipton Fund. We applied three of us for
2 Skipton Fund. It was me and two other people, and the
3 other two people belonged to, I would say -- nothing
4 wrong with that -- it was two of them was my very
5 close friend, white, and it was me. But they have
6 been given the fund (a) on their first application.
7 Right? And I was refused. Right?

8 I was refused because they say I was born in
9 Pakistan and, therefore, I got the disease from there.
10 But we are saying that, you know, the gentleman just
11 said -- asked her that, you know, "Where you are
12 born?" To me, I was born in a very clean atmosphere
13 in Pakistan, and the place was called Lyallpur, which
14 was -- you know, the person who was there, they built
15 a new city, Lyallpur, on his name, and it was a very
16 clean atmosphere, very clean when I left Pakistan.
17 And I went back again -- I hardly been back to
18 Pakistan.

19 So they are saying that, you know -- I always
20 get confused when they say that to me, "Oh, because
21 you were born in Pakistan and you got it". I'm sorry
22 to say that it is not the case. It is unfair to say
23 that. You know, when they write, "Oh, you have been
24 refused because you were born in Pakistan". Excuse
25 me? What? Because I was born in Pakistan? And if

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1 I would have been born here and my name had been
 2 different and that? So it is a very confusing thing.
 3 You know? Yeah?
 4 And sometimes you are let down by the people, by
 5 the organisation, which I think we shouldn't.
 6 **MS FRASER BUTLIN:** Ghufrana, is there anything you would
 7 like to add?
 8 **MS GHUFRANA QURESHI:** Nothing can bring my mum back but
 9 I think it is about time somebody takes the
 10 responsibility; somebody puts their hands up and says,
 11 "Yes, we gave the blood. She did have a blood
 12 transfusion. She did get hepatitis C from that blood
 13 transfusion. She had cirrhosis, she had the cancer".
 14 Somebody has to take accountability and that's what
 15 I think.
 16 It does make me angry. It makes me very angry
 17 because, yes, she wasn't believed; she is the one who
 18 went through it, we are the ones who are going through
 19 it, and there's nobody taking accountability and
 20 that's what needs to happen, somebody needs to take
 21 accountability.
 22 **SIR BRIAN LANGSTAFF:** Thank you, all of you. I shan't
 23 thank you individually but can I thank you together
 24 Given that you have been asked about stigma and each
 25 of you has indicated that there is a particular

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1 that I can pass on to others if they need help. Thank
 2 you.
 3 **MS FRASER BUTLIN:** Sir, on Monday we will be hearing from
 4 experts from the Public Health Administration Group
 5 **SIR BRIAN LANGSTAFF:** So the Public Health and
 6 Administration Group experts Monday and I think
 7 Tuesday --
 8 **MS FRASER BUTLIN:** Monday and Tuesday.
 9 **SIR BRIAN LANGSTAFF:** -- of next week.
 10 10.00 am, Monday.
 11 (12.34 pm)
 12 (The Inquiry adjourned until 10.00 am on Monday,
 13 3 October 2022)
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1 problem in the communities of which you are also part
 2 with stigma, but it makes it all the more important
 3 for people with your experiences to be prepared to
 4 come here despite the difficulties, the difficulties
 5 of health, the difficulties of having had a stroke,
 6 difficulties of the deep emotions that have been on
 7 display, that you have been able nonetheless to come
 8 here and to say out loud what others may shrink from
 9 doing simply because they feel in some way
 10 disadvantaged by the system.
 11 So it is very important, all the more important
 12 that you have had the greater challenges in coming
 13 forward to tell your story, and it is not easy for
 14 anyone, let alone for yourselves. So thank you very
 15 much.
 16 **MS GHUFRANA QURESHI:** I want to say thank you to
 17 everybody, even during the break, the support I have
 18 got and, again, there is that connection. So thank
 19 you, everybody.
 20 **MR WAQAR AHMAD:** I appreciate everyone. I got a lot of
 21 help from all of you and it makes me more stronger to
 22 go out and fight for the people. Thank you.
 23 **MS REGINA CHEPTANUI:** Thank you very much. As you know,
 24 many of us are on the same road and when I was asked
 25 to come and speak, I was scared, but now I am strong

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